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ABSTRACT

This newsletter focuses on the theme of early intervention which infants and young children with special needs in nine brief articles: "Early Intervention: A Matter of Context" (Samuel J. Meisels); "Early Intervention Research: Asking and Answering Meaningful Questions" (Jack P. Shonkoff); "From Case Management to Service Coordination: Families, Policymaking, and Part H" (Evelyn B. Hausslein et al.); "Part H Coordinators: Stresses, Satisfactions, and Supports" (Carol P. Berman); "Supports for the Process of Change in 'Program Families'" (Linda Gilkerson); "Finding Common Ground: Facilitating a Therapeutic Group for Diverse Parents of Young, Disturbed Children" (Lesley Koplow); "The Long Aftermath: Ethical Dilemmas in Resource Allocation Posed by the Care of Medically Fragile Young Children" (Edward A. Feinberg); "NCCIP: Achievement and Challenge--Remarks upon Receiving the Dolley Madison Award" (Urie Bronfenbrenner); and the presidential address of the president of the National Center for Clinical Infant Programs (Kathryn E. Barnard). Also included in the newsletter are reviews of nine publications and a conference schedule. (DB)

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NCCIP launches CityTOTS, a new training initiative
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Early Intervention: A Matter of Context

by

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The ideas in this essay represent a personal perspective on the future of early intervention. They are personal because they inform my actions and beliefs, because they have come to be all but intuitive to me at this point, and because I have chosen to make these statements without extensive citations or reference to the literature. Of course, these remarks are "professional" as well, since they reflect hard-won insights of students with whom I have worked and colleagues who have been laboring in this field for more than a quarter century.

I presented this perspective at the National Center for Clinical Infant Programs' December, 1991 National Training Institute and commit it to print at this time in order to establish a "benchmark" for myself and for others who may be influenced by these ideas. We need benchmarks in the field of early intervention to indicate what we know and what we still must learn. This is not the time to rest on past accomplishments or to assume that the important battles have been won or the essential knowledge accumulated. This is the time, rather, to take stock of our levels of achievement and understanding, and to extend our efforts beyond them.

I believe that both the past and the future of early childhood intervention reflect the gradual recognition, understanding, and application of a single concept: **context.** I will show how considerations of context illuminate three related areas:

- models of early intervention;
- assessment; and
- policy issues.

FAITH BOWLUS

Context

Nearly a generation ago, Urie Bronfenbrenner wrote

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a monograph entitled "Is Early Intervention Effective?" When it was published, in 1974, it opened new vistas and promised new hope. Bronfenbsenner told us that there were intervention programs that had been tried and had been studied, and that there was evidence that these programs did help children. Moreover, the most effective of these programs were those that actively involved the parents of children in the intervention. The "stamp of approval" was awarded, a successful plan was outlined, and a whole new world seemed to be awaiting us (Bronfenbrenner, 1974).

Nevertheless, for almost 20 years we have continued to stumble over the issue of "efficacy," which I call the "Big Question" of early intervention. Many of my colleagues concur that this is actually a pseudo-question. It was not a poorly-formed question in 1974, when Bronfenbrenner prepared his monograph. But it is now, because "Early Intervention" has changed and evolved and so has our understanding. Early intervention does not refer to something singular, but to a complex, multifaceted, and dynamic set of phenomena.

The complex character of early intervention suggests many questions related to the Big Question. For example, for whom is a particular type of intervention effective? When is it effective? Where is it effective? Should only one kind of intervention take place? Who should intervene? How long do effects of intervention last? Is intervention more effective if families are involved? Over what period should intervention occur? What does "effectiveness" mean?

In other words, the Big Question is not a single question. Many forms of intervention can occur in a child's life. For some children one approach is helpful. With other children, only moderate success is achieved, even after a wide range of strategies is applied. For most children, intervention is a multifaceted experience that involves changing immediate and proximate environments in order to enhance growth and development.

Yet, if there is one common thread that links successful intervention programs, it is that they do not treat children as isolated individuals. I will even take the risk of claiming that this deserves to be an axiom of early intervention: The needs of children served in intervention programs can only be fully understood within a family, social, and community context (see Sameroff & Fiese, 1990).

This generation's social scientists have confirmed (though some may claim to have "discovered" it) Bronfenbrenner's insight that children are not isolated beings. Rather, children are members of highly particular social systems, systems that are sometimes remarkably nurturant, but that are also potentially disturbed or even dysfunctional. We have learned that to intervene effectively with children is to intervene with them in context; nothing less will suffice.

Attention to context is necessary for mediating the forces, biological and environmental, that have both adverse and ameliorative impact on young children. I will expand on this through examining models of intervention.

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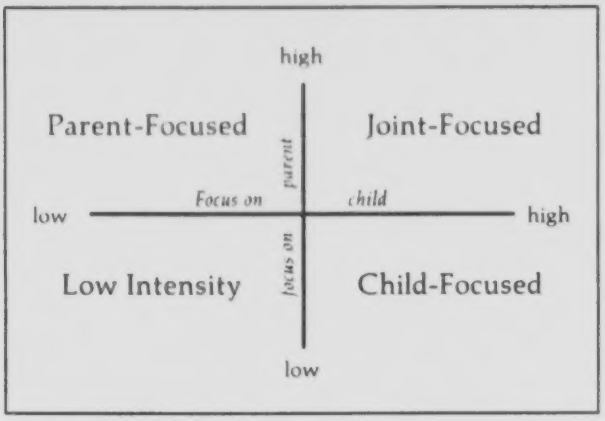
Models of intervention

This figure depicts the varied universe of early intervention. Rather than using a unidimensional continuum, in which either the child, the parent, or the family is made the target of intervention—and to the extent one is intervened with, the others are not—this figure shows a two-dimensional model that includes a focus on child and parent simultaneously.



The two dimensions are, first, the primacy of intervention with the parent (ranging from high to low), and second, the primacy of intervention with the child (also ranging from high to low). My contention is that the most effective intervention programs—those most attuned to context—will focus attention jointly on parent and child. I do not mean to suggest that all intervention designs are equivalently focused on the parent and child, because an intensity dimension is also involved. But this model allows us to construct and to analyze intervention programs with attention devoted to the child in context (see Meisels, Dichtelmiller, & Liaw, in press).

Another way to think about the issue of context is to devote attention to the participants' experience of intervention—to what happens *within* each of the models. My colleague and former student, Fong-ruey Liaw, has identified three approaches to intervention: Contacts, Exposure, and Active Experience (Liaw, 1991). The Contacts approach focuses on the extent of the participants' compliance with the intervention (e.g., the sum of the total home visits, support group meetings, and days in attendance at an intervention program). The Exposure model looks at the exposure of parents and children to the intervention activities (e.g., the average number of activities to which the parent was introduced at each home visit, and the average number of activities to which the child was introduced in a child development program). The Active Experience model focuses on the participants' actual experience of the intervention (i.e., the parent's *interest* in the intervention activities and the child's *mastery* of intervention tasks).

The first two approaches—contacts and exposure—reflect the child- and parent-focused models shown in the figure, including the low-intensity model. But the Active Experience model is different. It argues that it is not the number of contacts the participants had with an intervention program or the exposure of children and parents to activities that matters; rather, it is the interest in and mastery of program activities and experiences that are critical for the success of an intervention in promoting development.

To test these hypotheses empirically, Liaw reanalyzed the data from the recently completed Infant Health and Development Program (IHDP). This multi-site randomized trial included 985 low birth weight premature babies. Liaw examined results from hierarchical regression analyses on children's 36-month Stanford-Binet IQ scores. These analyses were structured around the three competing approaches mentioned above, approaches that

Editors' Note:

This issue of *Zero to Three*, focusing on the complex phenomenon known as "early intervention," appears five years after the enactment of Part H, the infant/toddler section of legislation then known as the Education of the Handicapped Act and since renamed the Individuals with Disabilities Education Act. Part H was reauthorized in the fall of 1991.

The contributors to this issue examine what we have learned from five years' experience with Part H—and from the several decades of early intervention experience that provided both the empirical knowledge and the political momentum to make Part H possible in the first place.

Contributors include parents, advocates, researchers, practitioners, educators, administrators, and providers of technical assistance. In addition to "looking at the numbers," they have listened to people—and they have captured the words and voices of Part H coordinators, parents, therapists, policymakers, and others who are "in this together," working to support the development of infants, toddlers, and their families.

What strikes us as most remarkable about the articles in this issue is that each contributor raises new questions for the field. None is easy to answer; each is important. How can ethical principles guide us in supporting children and families through the "long aftermath" of extreme prematurity? What kinds of early intervention approaches are most helpful to what kinds of young children and families? What supports do early intervention front line staff and agency administrators need in order to offer effective support to families? How can families of diverse backgrounds find common ground—with each other, and with professionals?

New questions are like new babies. They keep us awake at night, but they make life interesting. As always, we invite readers to share with us their own perspectives on the observations and questions raised in this issue of *Zero to Three*—and to suggest other aspects of early intervention that should be explored in these pages in the future.

reflect the participants' experience of the intervention. The results, presented in Table 1, give the proportion of children's developmental progress that can be accounted for by each approach to understanding the intervention experience (i.e., the R^2 change above and beyond the effects of initial background factors and children's 12-month cognitive ability).

Table 1

Increase in the Variance (Total R2) of 36-Month Stanford-Binet Scores Accounted for by Three Models of Experience of Intervention in the Infant Health and Development Study (IHDP)

I. Contacts Model	.53***
II. Exposure Model	.53***
III. Active Experience Model	.65***

Liaw (1991)

The Active Experience Model accounted for 12% more of the variance in children's IQ scores than the other two models. These data provide empirical substantiation for the jointly-focused intervention model presented earlier. These results also suggest that children's development is better predicted by the extent and quality of the child and family's active experience than by the number of contacts with the intervention staff, or the degree of exposure to intervention activities. In short, intervention program design must acknowledge and foster the active role and involvement of participants in the intervention.

To generalize from this, the jointly-focused, active experience model appears to be a more powerful approach to understanding the operation of an intervention on its participants than the alternative models, and it is probably a more significant way to intervene with children and parents to enhance development. These data indicate that children's developmental progress depends on active engagement by both parents and children in early intervention activities. This active engagement is most likely to occur when program designers and staff pay attention to the lived context of children and families.

Assessment

What role does context play in assessment? It is well-known that there are many problems with assessment of very young disabled and developmentally at-risk children. Some of these problems are directly attributable to the lack of attention to context (see Meisels & Provence, 1989). We see this particularly in what I call single-factor approaches to identification. Single-source or single-factor approaches designate infants and toddlers as being at developmental risk if any one of the following or similar conditions is met:

1) The child has experienced a high-risk biological insult (e.g., preterm birth, NICU admission, anoxia, poor prenatal care, etc.).
2) The child has been reared in a high-risk environment (including the family's economic situation and the age and education of the mother—any of which can have negative developmental consequences).
3) The child fails a screening test (almost none of which are valid for use in isolation to make accurate identification of very young children at risk).

Such approaches, or their variants, are in widespread use, and have major implications not only for assessment, but for establishing eligibility criteria as well.

What are the problems with single-factor approaches? First of all, biological risk is not a unitary construct or syndrome. There is no such thing, for example, as a "prematurity syndrome"—the risks of prematurity can be subdivided by birthweight, gestational age, medical diagnosis, and severity and chronicity of disease. Moreover, when biological insults occur, they can often be ameliorated by a nurturing environment. Second, environmental risk or poverty alone is not a sufficient condition for the development of serious coping problems or developmental delay. It has been shown that although 75% of mild mental retardation occurs among the poor, less than 10% of the poor are likely to be retarded (Ramey & MacPhee, 1986).

Third, single sources of data that are available from screening instruments are usually inadequate for making accurate predictions of risk or disability in the first three years of life. Assessments of development in the first few years of life are extremely inferential. The more sources of data that are tapped, the more adequate and useful will be the conclusions drawn from the assessment.

In contrast to the use of single sources, I propose that we adopt a multifactorial approach. There are numerous reasons for this, all supported by extensive research. For example, most isolated events or factors that occur early in a child's life do not have a continuing impact on development. Second, dynamic developmental changes occur in the first three years of life. Third, events such as preterm birth, neonatal hospitalization, or being born into poverty do not alone imply that a child's developmental potential will be compromised. Fourth, screening instruments are brief and highly inferential. Fifth, problems that have their origins in the caregiving environment usually cannot be identified by screening instruments alone. And finally, late-appearing manifestations of risk may not be detected by a single data source. All of these constitute reasons for rejecting a single source of data taken at a single time point as a valid means of identification or evaluation of infants and toddlers.

In short, we must begin to construct multiple risk indexes, rather than rely on data about single risk factors. These multiple risk indexes would be structured around the following types of data: biological variables, e.g., moderate to severe perinatal stress, or congenital problems at birth; caregiving factors, e.g., low levels of maternal education, standard of living, or family stability between birth and age 2; other behavioral variables, e.g., maternal ratings of very low or very high infant activity level; and delayed development, as measured by various psychometric instruments.

A simple example of what can happen when we combine multiple sources of data in attempting to make predictions about developmental risk may be useful. Laura Henderson and I studied the Early Screening Inventory (ESI; Meisels & Wiske, 1983), a preschool developmental screening instrument. In a pilot study of 90 four and five year olds, we combined the data from the individually-administered ESI with information obtained from a brief Parent Questionnaire (PQ) that accompanies the test. Table 2 provides this information:

Table 2

Contribution of the Parent Questionnaire (PQ) to Identification of Children At-Risk on the Early Screening Inventory (ESI)

Number of Misclassifications:

ESI - 14/90 (all overreferrals)

PQ - 22/90 (all but one overreferrals)

ESI+PQ - 6/90 (all but one overreferrals)

Henderson (1991)

This table shows the number of misclassifications, using the McCarthy Scales of Children's Abilities as an outcome. First, the ESI alone, which has 14/90 misclassifications (all overreferrals), then the PQ alone, with 22/90 misclassifications (all but one an overreferral), and then the ESI and PQ combined, in which the misclassifications drop dramatically to only 6/90. These figures show that there is a two- to three-fold increase in accuracy when we screen the child directly, and combine this with systematic perceptions of the child's performance as seen through the parent's eyes. In this multiple-source model, the accuracy of our predictions of development are enhanced significantly. Of course, predicting the developmental course of infants and toddlers is a greater challenge, and the amount of data and the number of sources to be explored must be more extensive.

In short, extending our efforts in assessment means devising systems of identification and evaluation that are multidomain, multisource, and multicontextual. Again, context is the key.

A new generation of programs

Finally, let's turn to policy issues in early intervention. In the first five years of planning for the implementation of Part H of P.L. 99-457, the field has been concerned with: defining recipients, analyzing costs, understanding family involvement, developing interdisciplinary cooperation, determining how to respond to cultural and linguistic differences in service recipients and service providers, maximizing program flexibility and controlling program intrusiveness, developing personnel, and working on transitions to programs for older children.

The range and extent of these issues underscore one of the most important lessons that we have learned, which is that intervention is not a monolithic phenomenon. In a continuum of ascending intensity, early intervention can include any combination of: phone monitoring, information and referral, periodic reassessment, brief home visits, activity centers, parent support groups, home-based intervention, center-based intervention, parent counseling, and specialized therapy. This whole spectrum constitutes early intervention. If nothing else, it is obvious that intervention is not a simple formula that can be followed universally.

The idea that there is a "right" way to intervene with infants is outmoded. We have gone beyond the "discovery" of the family and the rejection of single causal models as adequate explanations of delay, disorder, and disability. Now we must accept the responsibility to create new early intervention approaches that are sensitive to our current contexts. Gina Barclay-McLaughlin, an NCCIP Fellow and a current University of Michigan student, and I have begun to conceptualize this new "generation" of early intervention approaches. The first generation of programs was nurtured in the 1960s and early 1970s, and many of the features of these programs are still with us today (see Shonkoff & Meisels, 1990). These are basically hierarchical models, in which the "Lead Agency," or professionals, are at the top, and the child/family is at the bottom. Previously, these approaches were located within individual programs; now they have been elevated to the status of federal regulation and public policy. Without rejecting the "First Generation," which does correspond to the needs of some families and communities, we must begin to elaborate and refine a Second Generation of intervention models.

Here are the conceptual foundations of these two generations:

Conceptual Foundations of Early Intervention

First Generation	*Second Generation*
1) Hierarchical	1) Multiple lines of authority
2) Single agency	2) Multiple agencies
3) Preschool	3) Continuous beginning prenatally
4) Child-focused	4) Family-focused
5) Parent-targeted	5) Intergenerational
6) Cognitive emphasis	6) Comprehensive approach
7) Curriculum-driven	7) Individualized
8) Professional providers	8) Professional providers and community
9) Focus on individuals	9) Focus on the community
10) Federal initiative	10) Public/private initiatives

In order to implement these Second Generation models, many changes must occur. We must design models that account for greater diversity of needs; offer more respect for individual differences; embody different governance structures; foster different approaches to training; contain totally different roles for families; rely on different levels of responsibility and leadership from diverse social services; and generally reflect different relationships between recipients of services, professionals, lay professionals, researchers, and policy makers.

As we review the efforts of the past, and as we anticipate the needs of the future, we can see a distinct need for a better match between the child and family's lived context

and the context of early intervention, with particular attention paid to the manner in which services are delivered. It is essential that we shift the way that systems and structures are organized so that they work more effectively for families. No longer can we consider the child as isolated from his or her family. No longer should we attend to the needs of parents without also recognizing that they must know how to respond to the changing needs of their children. No longer is it appropriate to follow the dictates of a theoretical view of intervention without questioning its relevance to a particular child and family's social and community situation. Rather, we must foster highly individualized programs of intervention that consider the needs of children and families in tandem, and that seek to address these needs through theoretically-driven and empirically-substantiated models that are consistent with the family's world.

Instead of searching "out there" for the "best" intervention or assessment model overall, we must pay systematic attention to the child and family in context. As we learn to appreciate and intervene with their context, we will become more successful in enhancing development and strenghthening families.

References

Bronfenbrenner, U. (1974). *Is early intervention effective?* Washington, D.C.: Office of Human Development.

Henderson, L.W. (1991). *Parental involvement in the developmental screening of young children: A multiple risk perspective.* Doctoral dissertation, University of Michigan, Ann Arbor.

Liaw, F. (1991). *The efficacy of early intervention for low birth weight infants: What works, how, and for whom?* Doctoral dissertation, University of Michigan, Ann Arbor.

Meisels, S.J., Dichtelmiller, M., Liaw, F. (in press). A multidimensional analysis of early childhood intervention programs. In C. Zeanah (Ed.), *Handbook of infant mental health.* New York: Guilford Press.

Meisels, S.J., & Provence, S. (1989). *Screening and assessment: Guidelines for identifying young disabled and developmentally vulnerable children and their families.* Washington, D.C.: National Center for Clinical Infant Programs.

Meisels, S.J. & Wiske, M.S. (1983). The Early Screening Inventory. New York: Teachers College Press.

Ramey, C. T., & MacPhee, D. (1986). Developmental retardation: A systems theory perspective on risk and preventive intervention. In D. C. Farran & J. D. McKinney (Eds.), *Risk in intellectual and psychosocial development (pp. 61-82). Orlando: Academic Press.*

Sameroff, A.J. & Fiese, B.H. (1990). Transactional regulation and early intervention. In S. Meisels & J. P. Shonkoff (Eds.), Handbook of early childhood intervention (pp. 119-149). New York: Cambridge University Press.

Shonkoff, J.P., & Meisels, S. (1990). Early childhood intervention: The evolution of a concept. In S.J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood intervention* (pp. 3-31). New York: Cambridge University Press.

NCCIP TO LAUNCH CITY TOTS (TRAINING OF TEAMS) PROJECT

The National Center for Clinical Infant Programs will launch a new training initiative in 1992-93, with support from the Prudential Foundation's Focus on Children. NCCIP's City TOTS (Training of Teams) Project is designed to assist teams from participating cities to improve the training available in their communities for practitioners who work to support the development of inner-city children from birth to three and their families. Applications to participate in City TOTS will be invited from Atlanta, Boston, Chicago, Houston, Jacksonville (FL), Los Angeles, Minneapolis, Newark, Philadelphia, Phoenix, San Francisco, and Washington, D.C. The Prudential Foundation's newly developed Focus on Children program area provides grants to improve the lives and living conditions of children.

Building on the experience of NCCIP's 1988-90 TASK (Training Approaches for Skills and Knowledge) Project and the 1990-91 Training of Trainers Intensive Summer Seminar, the City TOTS initiative begins with several core assumptions. It recognizes that training professionals to be effective providers of high quality services to very young children and their families involves:

- the integration of knowledge from multiple disciplines and sources;
- modeling the development of supportive relationships; and
- the encouragement of self-awareness and reflective practice.

Teams selected to participate in the 1992-93 City TOTS Project will:

- plan a training initiative for infant/family practitioners in their city that is designed to take advantage of local strengths and address specific community needs;
- participate in a week-long residential seminar in the fall of 1992, which will emphasize infant/family and parent/professional relationships as a focus of training for professionals; and
- implement and evaluate their planned training projects during the nine months following the residential seminar, with continuing assistance from the National Center for Clinical Infant Programs.

During the two-year City TOTS project period and continuing beyond it, ongoing communication among participating city teams, NCCIP Board and staff, participants in NCCIP's 1990-91 Training of Trainers initiative, and NCCIP's national network of individuals and institutions will allow participating teams to take immediate advantage of new information and resources. At the same time, lessons learned from the City TOTS project and its evaluation will be disseminated to inform evolving state and national training policies and practices.

Detailed information about all phases of the City TOTS Project and team application packets will be available from NCCIP in early spring, 1992.

For more information, contact Linda Eggbeer or Emily Fenichel at NCCIP, tel: (703) 528-4300, FAX: (703) 528-6848.

Early Intervention Research: Asking and Answering Meaningful Questions

by

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In the five years since the enactment of Public Law 99-457, researchers interested in early childhood intervention have learned that many of the most meaningful questions about this complex phenomenon are extraordinarily difficult, if not impossible, to asnwer definitevely. Indeed, most of the important gains in service delivery thus far have been achieved as a result of effective advocacy, rather than because of compelling scientific evidence. Now, as we confront growing economic distress accompanied by increased scapegoating of those who are vulnerable and dependent upon others for support, decisions about the allocation of limited resources for young children with disabilities and their families are becoming more contentious.

As advocates, it is appropriate that we begin to ask some hard questions. For example: Are we using scarce public resources for early childhood intervention in the best possible way? Are there alternative approaches that might result in greater good for larger numbers of children and their families? At the same time, as scientists, we must be sure that we are asking important questions, even if they are difficult to answer. For example: How can we best measure the development of competence and a sense of self-worth in young children with developmental disabilities? How can we best assess and support the adaptive capacities of their families? The challenge for the field of early childhood intervention in the 1990s is to wear both hats—to balance the faith of the advocate and the skepticism of the scientist in an effort to best serve young children and their families.

This article draws largely on the experiences of the Early Intervention Collaborative Study, an ongoing longitudinal investigation that began in 1985. In this study, we have tried to ask "important questions" and, indeed, to sharpen our inquiry as our understanding has increased. As we have followed 190 children and their families enrolled in 29 early intervention programs in Massachusetts and New Hampshire over the past seven years, we have focused on two major research goals:

- To investigate the correlates of vulnerability and resilience in children and families—asking why some children and families do better than others, and why some do worse.
- To assess the mediating influences of specific service experiences on both child and family outcomes.

The findings that follow come from our analysis of the first year of experience in an early intervention program, for both children and their families. Greater details on this initial phase of the study are presented in a forthcoming monograph (Shonkoff, Hauser-Cram, Krause, & Upshur, in press).

The complexity of the early intervention experience

One of our most important findings about the experience of an early intervention program raises significant questions about the interpretation of previous research on service efficacy, and has considerable implications for further investigation. Specifically, we learned that the children and families in our study received such a wide range of services, in such different settings, and with such varying frequency that it is meaningless to talk about an "average" or "typical" early intervention experience. Early intervention programs are complex, and many families are involved in multiple service systems. Sometimes formal intervention has a major influence on the life of a young child and family; sometimes it may be relatively inconsequential and overwhelmed by other forces. As practitioners, we continue to appreciate the importance of an individualized service approach for each child and each family. As researchers, we have learned about the importance of looking closely at the actual services received by different subgroups of children and families.

Child change during the first year of intervention

Building on a perspective suggested by Zigler and Trickett (1978), we investigated the emergence of child competence based on two dimensions—"personal development" and "meeting societal expectations." We defined personal development through assessments of cognitive behaviors, as they are measured traditionally, as well as motivational behaviors, including spontaneous play, mastery motivation, and problem-solving skills. We defined a child's ability to meet societal expectations based on both functional behaviors (e.g., communication, motor performance, and self-help/adaptive skills) and interactive behaviors (i.e., mother-infant interaction and later interaction with peers).

The 190 children in our study sample included infants and toddlers with Down syndrome, motor impairment, or developmental delay of uncertain etiology. As we examined the emergence of competence during their first year of early intervention, we discovered that the range of rates of change was extraordinary. Indeed, we found it misleading to talk about "average change" for the group as a whole. Some gained a great deal, whereas

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others did not change at all. In attempting to explain which children did better and which did not do as well, we found (across all outcome measures):

- Greater gains in children born prematurely (probably representing "catch-up" growth) and in children with less severe impairment.
- Lesser gains in children with more severe impairment and in those with seizure disorders.

The smaller gains in children with seizure disorders remind us how crucial it is to consider health issues in the context of early intervention services—a fact that has been ignored in most of the early intervention literature to-date.

As we looked for patterns of service delivery that correlated with differential child change, we recognized that we could draw only limited conclusions since we had no control over the services children received as this was a non-experimental, naturalistic study. Nevertheless, we did find that greater gains in cognitive development, as measured by the Bayley and McCarthy Scales, were associated with services provided individually rather than in groups, and primarily through a single discipline supported by a multidisciplinary team. While these findings are correlational observations rather than well documented cause-effect conclusions, they serve to reassure those who believe in simpler models of intervention for very young children (after one year of study, the sample children had a mean chronologic age of less than 2 years and an average developmental age of 14-15 months). Thus, infants in early intervention programs who interact with only a few staff members may not be shortchanged, if the staff have access to consultation from a range of disciplines.

Dimensions of family adaptation

To learn about the experiences of our sample families, we collected data from both mothers and fathers across five dimensions:

- Locus of control—parents' beliefs about what might be likely to cause change in their child
- Family functioning—parents' perceptions of their family's adaptability and cohesion
- Social support—both the size and the perceived helpfulness of a family's social network
- Parenting stress—parents' perceptions of their own personal stress around parenting, as related both to the characteristics of the child and to their own performance in the parental role
- General impact of the child's disability on the family—social relationships within and outside the family, personal strain, and financial impacts

Reinforcing the pronouncements of many advocates, the families in our sample (on average) demonstrated overall normative adjustment during their first year of experience in early intervention. It is important to remember, however, that this does not mean that the sample parents did not experience stress. Rather, it serves as a reminder that all families with infants and toddlers experience some degree of stress around their parenting roles. Once again, however, we did find interesting subgroup differences:

- Parenting stress reported by fathers tended to be focused on their feelings of attachment to their infants and on aspects of their child's temperament such as adaptability; mothers expressed less distress related to the temperamental characteristics of their child, and more focused on their parental functioning, effects on their marriage and families, and sense of social isolation.
- Parenting stress high enough to warrant a referral for mental health services (for a sample subgroup) was associated with less cohesion and adaptability within the family and with support networks that were perceived as less helpful; it was *not* associated with the parents' marital status or with the type or severity of the child's disability. Thus, it appeared that the families who reported high levels of stress may very well have been experiencing problems before the birth of their child with a disability.

We also discovered only modest change, on average, in mothers' skills in teaching their infants during the course of their first year of intervention. This finding suggests the need for ongoing attention to the process of parent-child interaction in this vulnerable population.

When we looked at correlations between early intervention services received and changes in families, several clear patterns emerged:

- More home visits were associated with greater decreases in maternal parenting stress
- More center-based services were associated with greater increases in the size and perceived helpfulness of maternal personal support networks
- Professionally-led parent groups were a mixed experience; they were perceived as extremely helpful for some families, but as a source of increased stress for others

Yet again, the match between family and service, between service approach and intervention goal, seemed critical. The essential question is not, "What is the best form of early intervention service?" but, rather, "What are the best ways to achieve specific goals for certain types of children or families?"

Implications of our findings

After one year of early intervention experience, 190 infants and their parents taught us a great deal about the heterogeneity of children with disabilities, the adaptability of families, the variability of services, and the complexity of assessing and interpreting developmental change.

Researchers can draw three sets of implications from our findings. First, we must keep in mind the **complexity of the task of assessing meaningful child and family change.** It is easy to count the number of blocks a baby is able to stack. It is much more difficult to measure his or her level of motivation or "learning style." Even our best assessments of child and family functioning are

limited, and the challenges of interpreting data on human development and adaptation over time are monumental. Second, we must recognize the **difficulty of measuring service impacts** in a complex system in which everyone is getting something different and where confounding variables are ubiquitous. Finally, we need to **learn more about the mediators of change over the long term.** As difficult and complicated as it was to study one year of an early intervention experience, what really matters is what happens to the child and family over time.

Our first-year findings also have implications for service delivery. First, the central importance of **individualization** of the service experience resonated throughout our conclusions. Overall goals as well as specific objectives must reflect the rich variation among children and families, as well as the differences between mothers and fathers. Second, the modest level of change in mother-infant interactive behaviors during the first year of early intervention suggests the need for **more attention by service providers to the caregiver-infant relationship.** Indeed, this foundation for later child development, far more essential than specific skill development, seems to be an area of relative vulnerability for mothers of infants with disabilities. Finally, our findings suggest a need to **rethink the basis for equity in service delivery.** Enormous variation in the amount and types of services that families received was striking. What is less clear, however, is the extent to which that variation corresponded to families' needs and not to differential resource availability. Truly equitable distribution of scarce early intervention resources would not mean that everyone gets the same. In contrast, some families need and should get more; others may need much less.

An agenda for early childhood intervention in the 1990s

As we move into the final decade of the twentieth century, it is the shared responsibility of researchers, parents, practitioners, and policymakers to step back and to question many of the traditional assumptions that have governed service delivery for young children with disabilities and their families. It is **not** true that family maladaptation is widespread; yet some families could certainly benefit from considerable professional assistance. It **is** true that overarching goals can be the same for all children; yet their realization may vary considerably depending upon the nature and level of severity of the child's disability.

A central challenge for the 1990s is the need to reframe the questions that are addressed by researchers and policymakers. We should be asking not "How do children with developmental delays change as they grow older?" but "Why do some children and families do better than others?" We need to ask not "What is the best early intervention model?" but "What is the best approach to use for a particular child and his or her family to achieve a specified outcome?"

The agenda for early childhood intervention must also acknowlege and address persistent tensions in our evolving service systems:

- We are still, as a nation, ambivalent about the concept of "intervening" in the lives of young children and their families—the boundary between developmental facilitation and family intrusion may at times seem blurred.

- We have not reached a consensus on the definition of the target population to be served under the new law. Our study findings suggest strongly that a child's category of disability may be one of the least relevant factors for determining the need for early intervention services. Nevertheless, eligibility criteria continue to focus on child diagnostic labels, while children and families who are only "at risk" for developmental problems remain "at risk" for neglect by the service system.

- The process of changing the way in which parents and professionals interact in the human service system is more complicated than we might think. If we truly recognize and respect individual differences in both parents and professionals, we must be prepared for a process that will demand complex renegotiations of relationships.

- The costs and benefits of early intervention services must be measured and analyzed in terms of both dollars and moral values. In many cases, the monetary costs of early intervention can be shown to be off-set by later savings in special education or family support services. For some individuals, however, the benefits of investing public resources are reflected primarily in the moral imperative to provide assistance for those whose needs exceed their own adaptive capacities. In such cases, the monetary costs of service must be weighed against the moral costs of abandoning those who depend on public support. Comparable to the provision of nursing care with dignity for those who are elderly and frail, services for young children with more severe disabilities are provided not necessarily because it will save money later, but because it is the right thing to do.

The most meaningful questions before us are the most difficult to answer. They go far beyond asking "How many pegs can be placed in 30 seconds?" or "How would you rate the helpfulness of a home visit on a scale of 1-5?" Although such traditional measures certainly can be useful, they must be complemented by more creative protocols. It remains the responsibility of parents, service providers, and policymakers to articulate a vision of the future for young children with developmental disabilities and for their families. It then becomes the responsibility of researchers to translate that vision into conceptually-based research questions and hypotheses that can be tested in a scientifically rigorous manner. The marriage of advocacy and science in early childhood intervention is long overdue. With the proper balance between faith and skepticism, we will be ready to address the meaningful yet difficult questions that remain unanswered.

References

Shonkoff, J., Hauser-Cram, P., Krauss, M., and Upshur, C. (in press). Development of Infants with Disabilities and Their Families—Implications for Theory and Service Delivery. *Monographs of the Society for Research in Child Development.*

Zigler, E., and Trickett, P. (1978). IQ, social competence, and evaluation of early childhood intervention programs. *American Psychologist, 33,* 789-798.

From Case Management to Service Coordination: Families, Policymaking, and Part H

by

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Part H—the infant/toddler section of the federal legislation enacted originally as the Education for the Handicapped Act Amendments of 1986 and reauthorized in 1991 as part of the Individuals with Disabilities Education Act (IDEA)—provides a vehicle for families and professionals to work together toward a system of family-centered services for infants and toddlers with, or at risk of, disabilities. The Individualized Family Service Plan (IFSP), which must be responsive to families' concerns, priorities, and needs, and the requirement for service coordination may be the two features of Part H best known to families. Yet the opportunities for families to participate as full partners in state, and now federal, Part H policymaking may prove to be equally significant in their impact.

As most readers of *Zero to Three* are aware, the 1986 Part H legislation set in motion a five-year period during which states that chose to participate could receive federal funding as they moved in stages toward full implementation of the law and its regulations. Every year, each state and jurisdiction must apply for funds to the Office of Special Education and Rehabilitation Services (OSERS) of the Department of Education. In its application, the state assures the federal government that certain policies are in place for families and describes how the state plans to implement the elements of a service system that follows the law and its regulations. In each year of participation, more elements of the system must be operational. "Year Five," in Part H parlance, is the year of full implementation: all eligible infants, toddlers, and their families in a state are entitled to a full array of comprehensive, coordinated services.

Part H was first enacted in 1986, but relatively few states are in "Year Five" of implementation. Most states have needed an extended timetable in order to cope with the complicated process of state level policy development, negotiations with the Office of Special Education Programs (OSEP) within OSERS, and the budget tightening that has occurred in the face of current economic conditions. In the first years following the enactment of Part H, many parents, professionals, and policymakers had "Cadillac dreams," hoping that their interagency planning would create quickly a Part H system that fulfilled every possibility of this incredibly innovative law. More recently, planners in many states have had to limit their dreams in order to make any movement forward, and, indeed, to meet the minimum requirements of continued participation in Part H.

What has happened, in this process, to family participation in policy development? Parents joining original state or community Interagency Coordinating Councils were unlikely to have anticipated that intense negotiations within a state—about eligibility for services, for example, which was left largely for each state to define for itself—would be followed, once applications were submitted, by further negotiation with OSEP, to bring the state plan into compliance with federal interpretation of the law and regulations. Part H staff would come back

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to the planning group and try to change their words or strengthen their assurances or change their visions, so that state plans would be both comfortable for state policymakers and in compliance with OSEP standards. Were family members used as partners in policy development throughout this process? Were family-friendly policies evident in the actual language of state applications?

To find the answers, we examined the applications of 26 states (those available to the public as of November, 1991) for "fourth year" federal funds under Part H, looking for evidence of family-friendly policies regarding case management—or "service coordination," the term currently accepted under reauthorization of Part H. Fourth year applications are required to document state policy regarding Individualized Family Service Plans (IFSPs) and case management services for families. Moreover, case management is a cornerstone of Part H, and state-level case management task forces have been popular among parents around the country interested in participating in policy development (many parents have also served on IFSP task forces). Because the language of state applications is often terse, we also looked "softer" data sources, such as procedural manuals for local programs and technical assistance documents. We looked at training initiatives related to case management. We talked with parents themselves.

Our inquiries produced ample evidence of state policies that respect families and offer them many ways to participate in service coordination. To appreciate our findings fully, however, it is useful to review the evolution of family-centered case management.

From case management to service coordination

That families must satisfy multiple needs is not a new insight. In the early years of this century, "happy visitors" helped participants in settlement house programs find food, jobs, health care, and housing—basic supports that families still require. Some of these visitors (all were women) looked for the root causes underlying the immediate needs they observed. They became advocates and political change agents, challenging child labor practices, pushing for unionization of factory workers, and lobbying for women's voting rights. In the 1960s and 1970s, federally funded social services expanded, both for low-income families and their children and for individuals with mental retardation or emotional disturbance. Components of care were often fragmented and agency structures complex. During the movement toward deinstitutionalization in the fields of mental health, developmental disabilities, and mental retardation, case management was seen as a way to assist clients who were unable to advocate for themselves or to obtain the services and supports they needed in the community. In the 1980s, cost containment and "gatekeeping" became features of case management.

Significantly, all these variations on the theme of case management have shared two assumptions:

- The client is incapable of managing his or her own affairs.
- Since the system is a complex maze of uncoordinated and fragmented services, clients must be helped to work with the system (or restrained from misusing it). (Bailey, D.B., 1989)

The vision of family-centered case management or service coordination that has emerged through the implementation of Part H (and Maternal and Child Health Services Block Grant [Title V] legislation) is quite different. Part H encourages administrators and service providers to interact with families in such a way that they maintain or acquire a sense of control over their own lives and attribute positive changes to their own strengths, abilities and actions(Dunst, Trivette & Deal, 1988). Principles of family-centered case management (evidence of which we looked for in our review of Year IV Part H applications) have been outlined in *Guidelines and Recommended Practices for the Individualized Family Service Plan* (McGonigel, Kaufmann & Johnson, 1991):

- Case management models and practices in early intervention should reflect the implicit and explicit intent of the IFSP.
- Case managers must be able to perform multiple roles in their work with families.
- The ability to work in a linkage capacity is perhaps the most important role of a case manager.
- Case manager roles and functions should support and strengthen family functioning.
- A single case manager should be responsible for helping the family gain access to needed resources.
- Families need as much opportunity as possible to select a case manager as part of early intervention services.
- Case management practices should not create any additional burdens or strains on the family.
- Case managers must be provided with the training necessary to learn the skills needed to work effectively with families and with professionals from other disciplines.
- Effective case management practices will reflect the family-centered philosophy and conceptual framework of the IFSP.

Just as "service coordination" has seemed to be a more appropriate term than "case management" to describe activities that implement these principles, so a variety of terms are coming in to use to supplant "case manager" as a role description. These include: family support specialist, family service coordinator, resource manager, resource coordinator, care management coordinator, and support coordinator.

Most exciting for many parents and their partners in the Part H community, however, is the emerging conceptualization of a whole range of roles that parents might assume in service coordination under Part H.

- First and foremost, they are parents, there for the long haul as their own child moves through the service system.
- Second, parents are the primary decision makers about services needed for their child and themselves. They establish what their concerns, priorities, and needs are.
- Some parents may become official service coordinators or co-care coordinators for their own children (a possibility under the recent reauthorization of Part H that had been precluded by earlier regulations).
- Parents may become service coordinators for other children and their families.
- Parents may teach professionals and other parents to become service coordinators.
- Parents may advocate for better integration and more family-centered practices among health, education, and social services designed to support infants, toddlers, and their families.
- Parents may participate in the development of service coordination policy through participation in local or state Interagency Coordinating Councils.

Our conversations with parents and review of Year IV applications and other documents provided fascinating examples of how these possibilities for families are being realized in: 1) the process of policy development; 2) the language of state Part H applications and other public documents; and 3) operational models of family centered service coordination.

The process of policy development

We learned from talking to parents around the country that the most "popular" Interagency Coordinating Council task forces among families were those involved with developing policies for IFSPs and case management.

Parents usually felt that they had a voice and were truly able to contribute to the development of policies. They saw professionals on those task forces as eager to listen to the consumer/parent perspective. We were not able to tease out the respective influence of parents and professionals on the policies that emerged from these task forces. We speculate that family-centered philosophy statements reflected consensus among all task force members about the value of this approach, rather than parents overcoming significant resistance.

We were impressed to find states using creative strategies to encourage families' participation in policy development. One state held focus groups of families before any policy development began. The focus groups represented a first step to hear, informally, families' visions of what a service system should look like when fully developed. Another state developed a Family Support Committee of the Interagency Coordinating Council. The ratio of parents to professionals on the committee cannot be less than 7:3, and the chair must be a parent. "Individuals on the committee act," says the mission statement, "to represent the numerous families they serve and advocate for the needs of this population."

Family-centered language

As suggested by the title of this article, the shift in federal statutory language from "case management" to "service coordination" reflects an increasingly family-centered policy perspective on the national level. Some state Year IV applications not only use family-centered terminology but also reflect the philosophy and values of family-centered care throughout their descriptions of their planned service systems.

The first page of the case management section of Maryland's Year IV application includes this statement: "The case manager's goal is to enable the client to perform the role of identifying and using services as independently as possible."

Like a number of other states, Colorado found it important to articulate beliefs and values in its description of service coordination:

> The foundation of Colorado's case management/care coordination system will be built on values ... values which emphasize supporting and assisting families in gaining confidence and competence in meeting the challenges of everyday life. Case management/care coordination will be available in a partnership context which promotes family independence and interdependence in the community. Active involvement will be encouraged and providers will be offered training to increase awareness and skills which enhance their abilities to engage families at a comfortable pace.

Also in common with other states, including Arkansas, Hawaii, and New Mexico, Colorado emphasized the use of informal supports:

> Linkage and coordination of services will not only involve services rendered by agencies and professionals, but will encourage and facilitate utilization of natural supports in the community and a "families connecting with families" approach.

American Samoa's application said simply, "The value of parents as co-care coordinators is recognized ... and the family is the professional in recognizing the needs of their child."

Tennessee's application included this admonition to professionals: "Families' time is as valuable as your own."

Operational models of family-centered service coordination

In addition to articulating family-centered principles of service coordination, some states have taken concrete steps that encourage participation of families in this area. One state, for example, devised qualifications for the position of service coordinator that would place parents on at least an equal footing with professionals when competing for these paid positions. Service coordinators in this state are required: 1) to have been a resident member of the community for at least three years; and 2) to have experience with the early intervention system or be experienced raising a child with special needs. These criteria would give parents an advantage over someone with an academic degree but no experience or community roots.

Training for service coordination was another domain in which many states operationalized their commitment to family-centered practice. One state included training for parents as co-care coordinators in its Comprehensive System of Personnel Development. Several states are using Part H funds to pay parents to teach professionals to be service coordinators, and to teach parents to be active partners with professional service coordinators.

Next steps

Policy development and implementation in Part H is an ongoing phenomenon. Framers of the original legislation envisioned a step by-step process, but no one could have foreseen completely the diversity and complexity of states' responses to the statute and subsequent regulations. Now the reauthorization language suggests new frontiers for policy development.

As we looked for evidence of a family-centered philosophy in the policies of states hoping to enter the fourth year of Part H activity, we could recognize the principles, ideas, and language of many professional leaders in the field. But most influential, we are convinced, have been the families that participated in the process of policy development. They are the people who have kept Part H on track. And as families extend their participation in policy development from the relatively familiar IFSP and service coordination task forces to standing committees on finance and personnel preparation, we look to exciting developments ahead.

References

Bailey, DB (1989). Case Management in early intervention. *Journa Early Intervention* 13(2), 120-134.

Dunst, CJ, Trivette, C and Deal, A (1988). *Enabling and Empowering Fa Principles and Guidelines for Practice.* Cambridge, MA: Brookline B

McGonigel, MJ, Kaufmann, RK, and Johnson, BH, (eds). (1991). *Gu and Recommended Practices for the Individualized Family Service* Washington, DC: National Early Childhood Techical Assi System (NEC•TAS) and Association for the Care of Children's H (ACCH).

Part H Coordinators: Stresses, Satisfactions, and Supports

by

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All 50 states, and 10 other jurisdictions, have received federal funds under Part H (the infant/toddler section) of the IDEA (Individuals with Disabilities Education Act). All are at some stage in the development of comprehensive service delivery systems for infants and toddlers with disabilities and their families. And although neither the IDEA statute nor regulations provide a job description or even reference the position, every state or jurisdiction has a "Part H coordinator," designated by the Part H lead agency as having principal responsibility for implementing the law. Part H has been described as an experiment in federally mandated interagency collaboration, with much to be learned from its implementation in the various states and jurisdictions (Brown, 1990; Gallagher, et.al., 1988). The effectiveness of the Part H coordinators, individually and collectively, represents an important variable in this experiment, likely to influence in major ways the impact of the entire Part H program on young children and their families.

To learn more about the nature of the Part H coordinator's job and the experiences of the first coordinators, I used questionnaires, interviews, and supplementary materials to study the jobs and levels of job satisfaction among 39 Part H coordinators. Subjects included 10 "former" coordinators, who had been in the job for at least a year and who no longer held the position; nine "replacement" coordinators, who had accepted the position after someone else had been in the job for at least a year; and 20 "continuous" coordinators, who had remained in the job from the beginning of the Part H program.

The term "Part H coordinator"

The term Part H coordinator appears to have evolved out of common usage rather than a legal basis. Although the term "Part H coordinator" is used and recognized widely, it is not typically the job title used by states themselves. The coordinator is called something like "project director" or "executive director, ICC (Interagency Coordinating Council)," or has a title that conforms to the context of the state bureaucracy, such as "early intervention specialist," "program manager," or "administrator." In some states, the coordinator's functions are shared by more than one person; in others, the Part H coordination job is only part of an individual's responsibility.

The job of Part H coordinator

The content of the Part H coordinator job has changed over time. For example, when Part H was new, much of the job involved making stakeholder agencies aware of the program's existence; in the last few years, the job has included negotiation of financial agreements among such agencies. In general, the coordinator's work includes some or all of the activities within each of the following clusters:

Interpersonal, interagency work:

- Negotiation; develop interagency agreements; define and designate authority to enter into formal agreements to assign financial responsibility
- Set up and organize council meetings, and other ICC staff work
- Conduct or serve on interagency and intra-agency committees and task forces
- Work closely with other staff in related programs, federal project officers, supervisor

Administrative work:

- Prepare reports and memoranda
- Fiscal administration: develop cost projections, prepare, review, monitor/maintain budgets
- Develop personnel actions
- Write proposals/applications; develop requests for proposals

Policy analysis, policy development work:

- Set goals, vision, and direction of the program
- Conduct research or review/interpret research findings
- Draft policy manuals/legislation
- Policy analysis; monitor state and federal legislation, review national research for potential impact on service system
- Advise department head
- Testify before state legislature

Quality control work:

- Review or supervise work of others
- Develop rules or guidelines
- Monitor for compliance; grant management/supervision activities; develop standards; develop lines of authority
- Advise Department management on pertinent issues
- Facilitate, conduct, or direct training
- Evaluate project activities; site visits

Public relations; communication related work:

- Respond to a variety of information requests from within and outside the state
- Conduct hearings; represent program in all legal proceedings
- Handle complaints
- Conduct or attend workshops, give presentations
- Develop materials; for example, public awareness brochures

- Confer with others: early intervention service providers, university personnel, parents of children with special needs, advocates
- Develop dissemination strategies

Many coordinators said they frequently prepared reports and memoranda, responded to requests for information from within the state, and reviewed or supervised the work of others. Several coordinators mentioned a desire to be involved in more frequent and/or more in-depth research activities. Although Part H coordinators are expected to help ensure the passage of enabling legislation in their states, only seven coordinators indicated that they testified frequently before the legislature. Twenty-one never did (some coordinators said that others in their agency generally were responsible for giving testimony.)

Some coordinators indicated that much of their work involved "teams" within their agency and bridging programs in their agency with others. Other coordinators, particularly those in states with small allocations of funds and few staff, found teamwork sorely missing from their jobs. Thirty coordinators indicated they see families of children with special needs occasionally, but only seven have direct contact families of children with special needs frequently. Contact with university personnel also tended to be occasional.

The context of the Part H coordinator's job

Given the number of variables that distinguish one state context from another, it was not surprising to find many differences from state to state in the Part H coordinator's job. On the other hand, I found a remarkable consistency in the kinds of contextual issues affecting the job.

Since the job requires the Part H coordinator to create systems change, the location of the coordinator's position within the state administrative hierarchy is a critical contextual issue. Their key roles in implementing new legislation notwithstanding, Part H coordinators in this study were usually far from the top of the hierarchy in state executive agencies. Coordinators in the sample generally reported to an individual whose rank was no higher than branch chief. Typically, the coordinator's supervisor was a high-level assistant to a unit head within a branch, within the executive agency that had been designated as lead agency.

Some coordinators did report directly to a Commissioner or Assistant Commissioner of the lead agency. Many were allowed to communicate directly with personnel above their level within the agency, while officially reporting to someone at a lower level. One Part H coordinator, for example, served as staff to the Interagency Coordinating Council, whose chair held a high position in the Part H lead agency. This coordinator was supervised by someone lower in the agency's bureaucracy, but direct access to the ICC chair was necessary and appropriate. Moreover, the ICC chair tended to authorize the Part H coordinator to communicate directly with individuals even higher in the agency hierarchy. This was all possible because the coordinator's relationship with her immediate supervisor was a trusting one. On the other hand, some coordinators were constrained from communicating, except through supervisors, with high-level agency officials, personnel in the governor's office, the press, and others who might help produce change.

One coordinator said that, until I interviewed her, she had not given much thought to the question of her place within the hierarchy and what this might mean for creating systems change. She reflected that the location of her office may have a negative impact on the progress of the program, and consequently, on her satisfaction in her work. Another coordinator observed, "I enjoy a fairly good position in the state political and administrative structure. I have had a chance to savor a difference, having held several positions within the bureaucracy. It's easier to administer (Part H) when in a position of higher visibility and a higher administrative structure."

The extent of a Part H coordinator's autonomy is not necessarily evident from the location of the office within the bureaucracy. I found some coordinators with "higher" placements constrained in their effectiveness because they worked under the authority of individuals who were uninterested in or even antipathetic to the goals of Part H.

All coordinators in the study were able to identify individuals who helped make it possible for them do their job or cope with failure. Support came from personnel within their agencies, family members, and individuals in "the Part H community," such as service providers, advocates, and parents.

A literal contextual issue for Part H coordinators is the physical space in which people are housed. A few coordinators indicated they liked their offices, mainly as compared to previous quarters, but complaints about shared office space, with a resulting lack of privacy, were common. One coordinator reported that she and her colleagues shared an office with employees of another program, with hardly any work to do. These officials devoted much of their time to cutting out paper snowflakes and pasting them on office windows. Some coordinators lacked the basic equipment and supplies needed to support the work. One coordinator, who was involved only at the early stages of Part H implementation, reported that the long time it took to acquire computers made it difficult to communicate or process information. At least three coordinators worked in buildings being renovated to remove asbestos. Part H offices were sometimes at a distance from others in the lead agency.

Travel, both within and outside the state, is a significant aspect of the Part H coordinator's job. Most Part H coordinators reported that they travel frequently; none said they never travel. Travel within the state may involve providing technical assistance to local programs or councils, monitoring programs funded by Part H, holding hearings, training, or otherwise bringing the state program to the regional and local

level. Regional and national meetings are frequent. At the beginning of the program or early in their tenure, coordinators looked on travel more favorably than they did later. Travel lost its appeal as its time demands conflicted with the need to stay in the office, building networks and communicating with peers.

Preparation for the role of Part H coordinator

I asked Part H coordinators about the training and prior experience that they had found to be helpful preparation for their Part H responsibilities. Three-fourths of the coordinators held masters degrees in disciplines including audiology, business administration, developmental disabilities administration, early childhood education, early childhood special education, elementary education, family life, nursing, occupational therapy, psychology, social work, and speech/language pathology. Six coordinators had doctoral degrees; four had bachelors of science degrees. Coordinators found generally that their previous work experiences were more helpful than their academic training as preparation for their Part H responsibilities. However, some Part H coordinators considered an academic background in early childhood, special needs, or family-centered approaches important, not only because it helped them to understand the rationale for Part H and to evaluate the quality of local programs, but also because a relevant academic background provided the coordinator with credibility among some constituencies.

Reflecting on their prior work experience, many Part H coordinators found that experience in interagency work, knowledge of state bureaucracy, and familiarity with the state legislative process were helpful.

Part H coordinators frequently cited specific skills that helped them meet their responsibilities. These included facilitation, communication, negotiation, administration, long range planning, budget development, grant writing, board and committee management, and policy planning. Personal qualities that coordinators found helpful in getting the job done included flexibility, the ability to defer immediate gratification and set long-term goals, life experience and maturity, sensitivity to the needs of families, leadership, tolerance for the cultures of various disciplines and agencies, and "savviness in manipulating" state government. Coordinators noted that the style of a bureaucracy can be frustrating for people who like to have (and are impatient to achieve) closure. It is difficult enough to gain approval for a new policy within a single agency. The Part H coordinator's task, which involves shepherding policy through a range of agencies, working with people at various levels of authority, requires both skill and patience.

Ideally, preparation for the job of Part H coordinator would include both academic training and bureaucratic experience. However, creative coordinators found ways of compensating for gaps in their personal backgrounds. Coordinators new to state bureaucracies looked for collegial support from mentors well versed in systems change and in the workings of state administration.

Common Features of the Part H Coordinator's Job:

Time pressure
Boundary spanning - across agencies and rank
Administrative work
Policy development
Program monitoring
Travel
Setting vision
Team work combined with independent work
Attend meetings

Variable Features:

Direct contact with families
Plan and implement research
Conduct meetings
Contact with legislative staff, legislators
Contact with governor's staff
Supervision of personnel
Opportunities for creativity

Useful Background:

Knowledge of systems
Understanding how bureaucracy works
Background in Early Childhood
Ability to negotiate
Understanding of financing issues
Long range planning
Budgeting
Grant writing
Board and committee management

Helpful Personal Characteristics:

Patience
Flexibility
Tolerance for ambiguity, criticism
People person - interpersonal skills
Resourceful
Strong written and oral communication skills
Leadership capability
Strong interest, commitment to children and families
Altruism

Helpful Agency Circumstances:

Sufficient staff
Sympathetic supervisor and agency
Adequate working conditions
Access to power
Rank
Support system

Part H coordinators who were experienced in government and committed to the program but who lacked knowledge of early childhood services called on others to work closely with the professional community when a solid knowledge base was important.

Job satisfaction and dissatisfaction

In my exploration of Part H coordinators' degree of satisfaction with their jobs (and in my efforts to understand what seemed a high turnover rate among coordinators in the first years of Part H), I used a theory of job satisfaction proposed in 1959 by Herzberg, Mausner, and Snyderman. These experts on organizational development suggest that "satisfiers" tend to relate to the *content* of a job (factors that provide motivation to work and accomplish goals that are valued by the individual worker), while "dissatisfiers" tend to relate to the *context* of the work. In this model, satisfaction and dissatisfaction are not seen as opposite points on a single continuum; rather, content and context are parallel constructs. One can be satisfied with the intrinsic nature of one's work and one's achievement (content), yet at the same time be stressed or frustrated by the extrinsic circumstances (context) of one's job. My study of major satisfiers and dissatisfiers of 39 Part H coordinators generally supported the usefulness of this model.

Satisfiers

- **Being able to achieve.** Nearly every coordinator identified programmatic accomplishments that were a source of satisfaction. Coordinators who were more satisfied with this job than with previous jobs identified many more achievements. Some Part H coordinators talked about broad organizational accomplishments ("creating an atmosphere of cooperation," "creating a vision," "influencing standards for programs") while others mentioned the achievement of specific milestones in the implementation of components of the legislation ("seeing the fourth year application on public review," "getting sign-off by agency heads on the interagency agreement.")

- **Creative work.** Thirty-four of the 39 coordinators who participated in the study were either somewhat or totally satisfied with the opportunity to be creative in their Part H jobs. One coordinator remarked, "In a way, the whole (job) is creative, though no one can see it. It has to seem as if *they* do it. You (the coordinator) have to be facilitative. You create opportunities for conversation, which lead to change." Another coordinator described having freedom and flexibility to be creative as a "privilege." She understood that not all bureaucratic jobs encourage creativity.

- **Getting recognition.** Some coordinators took pride in formal recognition for their efforts, such as commendations by state associations. Others found "quiet respect" more important than public acclaim. One coordinator was pleased to "be respected, even by people on the other side of issues." Another pointed out that part of being a good leader is gaining recognition for others. She said, "It wouldn't be helpful for me to be singled out. I don't need it or want it. I don't want to see jealousies coming from my having a 'star' role."

- **Promotion.** Some Part H coordinators said that being promoted was important to them, not only personally but also because higher status improved the visibility of the Part H program and increased their ability to navigate the state system. In at least one instance, promotion prevented resignation. Although many coordinators had received raises, often "step" increases during their tenure, nineteen coordinators in the study had received neither a raise nor a promotion as their responsibilities increased.

A mixed blessing

The Part H legislation and regulations place increasing demands on each state's Part H system during the course of the five-year planning and implementation period. Increased responsibilities were seen as a mixed blessing by Part H coordinators. The higher status, new work assignments, and increased staff brought as much frustration as fulfillment in the short run, although coordinators saw that larger staffs and increased program status would be helpful over the longer term.

Dissatisfiers

- **"Company policy" and management.** Coordinators mentioned a variety of dissatisfiers that shared the common characteristic of being imposed by authorities above them. Coordinators identified issues as global as state funding shortfalls affecting all human services and as specific as a lack of office supplies. What was telling was that some coordinators felt like helpless victims of bureaucracy; they had no say in shaping policy (for example, to allocate scarce resources) but had to live with the consequences of policy decisions made by others. A comment that seems to capture the angst came from a "replacement" coordinator whose predecessor had resigned because of similar feelings about the supervisor in question:

> I brought a lot of background to this job and know how it's supposed to work ... Decisions have been made (by my supervisor) that don't involve key players in other agencies. There is no interagency spirit, except in what I've been able to do to bring others on board to elicit support ... Those people think I know what's going on and am getting it done. (But) I can't go around (the supervisor) ... I end up looking like a liar ...

- **Job ambiguity.** Many coordinators observed that they had never been told what was expected of them in their jobs. For some coordinators, this ambiguity was not a problem—they assumed that they had the authority or permission to do what they thought was appropriate, and they did it, changing course if circumstances changed. Coordinators who looked to others for direction found ambiguity difficult. They made comments like "I was provided with no real direction." "I basically had to feel my way; nothing was clarified." "I'm penalized when wrong, but clarification only comes *after* something is not done."

- **Interpersonal relationships.** Although many coordinators found relationships with peers, superiors, and subordinates among the satisfying aspects of their jobs, those coordinators who lacked autonomy cited relationships with supervisors as a great source of dissatisfaction. Coordinators who had conflicts with members of their

state's Interagency Coordinating Council also described interpersonal relationships as a source of dissatisfaction.

Passivity seemed to be more of a problem than overt hostility. An agency head who was unsupportive of the Part H program might tend simply to ignore it. Coordinators found this behavior more frustrating than a straightforward battle, with an opportunity to argue one's case. Some coordinators described councils that never engaged in serious debate, seeming to go along with what the chair suggested, yet reneging when it came time to commit funds or sign an agreement. Some supervisors were described as permissive—until they needed to send a budget or legislative package forward. The interagency nature of Part H decisionmaking often added to coordinators' frustrations; several study participants wished they did not have to "get everyone to sign off on everything."

- **Physical working conditions.** Twenty-eight coordinators said that their physical working conditions affected their degree of job satisfaction; 21 of these were affected negatively. Most of these coordinators complained of crowding and lack of privacy, either for themselves or for their staff. Although this dissatisfier did not seem likely to lead a coordinator to leave the job, comments suggested that poor working conditions might diminish productivity.

- **Salary and status.** Thirty-seven of the 39 coordinators in the study said that salary was important or extremely important to them. A number of coordinators commented that they were paid less than they deserve, given the long hours, stress, and responsibility. However, an undervaluing of the coordinator position itself seemed to rankle more than the perception of being underpaid. One coordinator said, "(The job) is worth more than I'm paid, but salary is not what drives me. It's the level that (irritates me). My position description doesn't include supervision, yet I supervise (a number of people) and manage (a number of) contracts. It's not the dollars. It's the authority."

Satisfaction and turnover

Nearly 60 percent of the Part H coordinators in the study said that this job was more satisfying than previous work. Even among coordinators who had left the job, half considered the Part H position more satisfying than other jobs they had held.

The relation between satisfaction and turnover is not linear. Some combination of perseverance, stubbornness, and altruism has kept some very dissatisfied Part H coordinators in the job. One current coordinator who is less satisfied with this job than with previous work plans to stay "because I would feel like I gave up. I'm not at a point where I can leave and be happy with myself." She expressed disappointment that " ... it hasn't been the opportunity I thought it would be." One coordinator stays despite dissatisfaction because "no one else would submit to the torture" and too much is now personally invested in seeing the program succeed. Another said, "I stay because of the babies." Still another said, "I sort of feel a need to prove to myself I can do this."

No one difference between Part H coordinators who persist and those who leave is apparent. However, some factors seem cumulatively or collectively to contribute to greater dissatisfaction and unwillingness to cope with it:

- Half of the Part H coordinators who left claimed difficulty with access and relationships within the lead agency. Two coordinators resigned after mentors in powerful positions in their agency left.

- When turnover was due to dissatisfaction, there tended to be a key incident, "the straw that broke the camel's back," that precipitated resignation.

- Coordinators who persisted in their job tended to have stayed longer in other jobs as well, especially in other positions in bureaucracies. Those who left tended to have comparatively less bureaucratic experience.

- Coordinators who have remained in the job have had relatively good support within the Part H lead agency.

The job of Part H coordinator is not one that is accomplished easily or alone. Coordinators who have persisted in their jobs seem to have been in an environment that supports progress. The most satisfied coordinators have had someone in a position of power who was available to help them, or have been kept motivated by progress toward the implementation of the program itself. They relish the vision of Part H and anticipate improved services for young children and families because of their efforts.

Recommendations

Recommendations that were made by individual Part H coordinators or that emerged from the study as a whole concern both the coordinator's job and the Part H program as a whole.

Three sets of recommendations cluster around the position of the person charged with lead responsibility for Part H. These would apply to any comparable federal-state interagency initiative.

1. Bureaucratic issues

- States should consider increasing the rank, visibility, authority, and autonomy of the coordinator position.

- The commitment of the coordinator's *supervisor* to the success of the program should be assessed carefully. If the supervisor is hostile or apathetic, chains of command or placement of the program within the bureaucracy should be adjusted.

- State bureaucracies need to find ways to permit and reward creativity, perhaps through modifications in management style.

- Systems change, mandated by Part H, is unlikely to occur easily unless coordinators are permitted direct contact with legislators, media, and the Governor's office.

2. Clarification of job titles and responsibilities

- The term "Part H coordinator" should be clarified at the federal level to provide consistency in the way the position is viewed nationally and by each state. Findings of this study confirmed that the coordinator job is typically

a middle management position with considerable responsibility.

- Future legislation that creates interagency initiatives and calls for coordination should specify the job titles and responsibilities of those responsible for the coordination function.

- As an interim measure, state lead agencies should consider clarifying the responsibilities and titles of all those involved in Part H coordination, for example, designating "local," "regional," and "state" Part H coordinators.

3. Support for the coordinator's job

- Support should be viewed as including not only clerical and professional personnel to back up the coordinator, but also physical, intellectual, and emotional support.

- If sufficient staff to do the work is lacking and staff hires are not permitted, funds should be spent for consultants.

- Findings of this study and of the Carolina Policy Studies Program have indicated the need for training and technical assistance opportunities concerning leadership and systems change. This study suggests that mentoring and consultation on navigating the state bureaucracy and on negotiation skills should be made available to coordinators.

- Salary and rank should be comparable to other programs and commensurate with the coordinator's leadership function.

- Since network building is a critical part of the coordinator's job, private office space and appropriate equipment should be considered as basic necessities.

- A national study should be conducted to determine minimum staff requirements for the *coordination* job (as distinct from management of the service system). Findings and recommendations should be reflected in appropriations.

Three additional sets of recommendations that emerged from the study concern facilitation of the Part H program as a whole.

1. Fostering interagency vision sharing, collaboration, and creative problem solving

- Lead agencies and interagency councils should engage all constituencies of the program (families, agency administrators, private sector professionals, legislators, media, researchers, university personnel, and others) in celebrations of achievements and planning of next steps. Grant awards and the completion of agreements can be used as occasions to recognize progress and acknowledge the tasks ahead.

2. Affirming the commitment of the lead agency

- Findings of this study and others confirm the importance of the lead agency's commitment to the well-being of the program. Periodic affirmation of the commitment of the lead agency seems important, with shifts in lead agency responsibility where appropriate.

- States should consider the benefits of starting interagency programs in the Office of the Governor, or of having a rotation of leadership among agencies.

- In drafting future legislation that establishes lead agencies and/or interagency councils, legislators should build in mechanisms or incentives to ensure or encourage visibility and public support.

3. Program support from Interagency Coordinating Councils

- The newly legislated Federal Interagency Coordinating Council should help to gain increased public support for the Part H program, a need established by this study and research of the Carolina Policy Studies Program.

- State Interagency Coordinating Councils should recognize the value of their efforts in increasing public awareness, both to program accomplishment and coordinator satisfaction.

References

Brown, W. 1990. *Early intervention regulation: Annotation and analysis of Part H.* Horsham, PA: LRP Publications.

Gallagher, J., Harbin, G., Thomas, D., Wenger, M. and Clifford, R. October, 1988. *Major policy issues in implementing Part H (P.L. 99-457 /infants and toddlers/.* Chapel Hill, NC: University of North Carolina at Chapel Hill, Carolina Institute for Child and Family Policy.

Herzberg, F., Mausner, B., and Snyderman, B. 1959. *The motivation to work.* NY: John Wiley and Sons.

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The National Head Start Bureau and the National Center for Child Abuse and Neglect of the Administration for Children and Families announce the availability of funds in the areas of Head Start/University Partnerships, Correlates of Positive Outcomes for Head Start Children and Families, Field-initiated Studies in Child Abuse and Neglect, and graduate student research grants in both areas. This announcement will appear in the *Federal Register* in early spring. To receive the announcement and/or serve as a proposal reviewer or as a consultant on advisory panels, send your request to James O'Brien, Ph.D., The Head Start Bureau, Attn: Head Start Research, CC, P.O. Box 1182, Washington, DC 20013. If you wish to serve as a reviewer/consultant, include your social security number and indicate whether you are willing to input your resume on a Head Start-supplied diskette.

Supports for the Process of Change in "Program Families"

by

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In infant programs, we need to pay attention to two kinds of families: the participating family and what I call the "program family—the team, the work group, the staff. While we are learning that families participating in early intervention programs may be experiencing less stress than we might have anticipated (see Shonkoff, this issue), it is my observation that the other family—the program family—is highly stressed right now. There are many reasons why this is so: heavy caseloads, compounded by lengthy waiting lists; state budget crises, resulting in decreased program funding; increasingly complex family situations and community environments; and, given these systemic stresses, amazingly high expectations for ourselves, each other, and the families we serve.

Early intervention programs have been negotiating these challenges at the same time that they are engaging in a major shift in their philosophy and practice. Ann Turnbull and her colleagues at the Beach Center for Families and Disability have called this philosophical shift a "Copernican Revolution" in our thinking about serving young children with disabilities and their families. Just as Copernicus revolutionized our entire worldview when he placed the sun, instead of the earth, at the center of the solar system, so a startling reversal occurs when the family is in the center of the universe and the service delivery system is one of the many planets revolving around it.

While Copernicus understood the proper pattern or arrangement of the celestial bodies, it took Isaac Newton to discover the forces acting to keep the sun and the planets in place. And that is where I see the field of early intervention in the 1990's—ready for our own Newtonian Revolution, for the discovery of the structures and processes which must be put in place to enable us to sustain our newly re-conceived parent/professional relationships over time.

Support for the director

It is my firm belief that to support and sustain "program families" that serve participating families well, several safeguards must be put in place. First, we must build into each early intervention program unit a "healthy hierarchy." This is a clear administrative structure, with a designated leader, for every program, regardless of size. If a program is large enough, it should include team leaders for work groups, with a structure in place to support their roles.

Many early intervention programs, particularly smaller ones, were built by a team effort. Roles and role boundaries were quite open. Everyone pitched in to develop the program. Programs were characterized by flat organizational models, team consensus, and role symmetry. But although these program characteristics were strengths in the development phase of early intervention, they may be stresses as we enter the maintenance phase of long-term service delivery.

We need strong, courageous directors who know when to say yes and when to say no. At the Erikson Institute, self-knowledge is valued as a legitimate professional competency. Nowhere is this quality needed more than in the role of the director, for his or her strengths and weaknesses will be mirrored in the team's relationships and performance. One of the many essential roles that the director plays is to think about the group, its individual members, and its collective process. But someone must also be thinking about the director.

Recognizing infant program directors' needs for support, we initiated at the Erikson Institute a Supervisors' Forum for Directors. Originally, we thought the need was for support around clinical supervision, how to help staff with their work with families. What has emerged, as Judith Bertacchi and Fran Stott have worked with groups of directors over time (see *Zero to Three*, December, 1991), is a crying need for *administrative* consultation. Early intervention program directors need help in setting boundaries and enforcing limits; in dealing with anger and conflict; in working through their ambivalence toward their own roles as director; and, of course, in combatting the isolation that accompanies leadership. The peer support and strong mentors/role models provided by the Supervisors' Forum seem to be essential components of the supervisory/consultation process for women in leadership roles. We have come to see administrative support/consultation to the director as one of the essential, dynamic forces in this Newtonian Revolution in work with infants, toddlers, and their families.

Ongoing supervision

A second essential and sustaining force in early intervention programs is ongoing supervision. It is the director's responsibility to ensure that a clinically rich model for staff supervision is in place. What should this supervisory process look like? As NCCIP's Learning through Supervision and Mentorship Project is discovering (*Zero to Three*, December, 1991), supervision in infant/family practice may take many forms, but should always include three elements: reflection, collaboration, and regularity.

Recently, I had the opportunity to visit with Edna Adelson Fraiberg, one of the pioneers of the infant mental health movement. We talked about the group process and clinical supervision model that was present while she, Selma Fraiberg, Jeree Pawl, Vivian Shapiro and others were developing their ways of working with infants and parents together. What was it that made this group of professionals work so well together? Ms. Fraiberg said:

FAITH BOWLUS

It was a bit like a life raft mentality. We were all in there helping one another. When we'd be ready to dash out to a home visit, when the day had been particularly chaotic, there was someone to help you focus, to collect yourself. When you returned (to the office) and knew you couldn't do another thing until you talked it out, there was always someone with a cup of coffee to help you come back to earth.

This kind of work is just different from others. We left the book behind. We responded to families and let them lead us. Individual supervision sessions were standard. Additionally, our two-hour-per-week group meetings were inviolate. Selma ran a tight ship. She didn't allow a lot of speculation. She always directed us back to our observations, or videos, or detailed process notes. So much is subliminal; you're responding to signals you can't articulate without the eyes and ears of your colleagues. No one had the answer. We were all in there together. With all our goofs.

Reflection, collaboration, regularity. Ms. Fraiberg paused and said:

You know, what I miss most in retirement are those relationships in between the appointments. People with whom it was safe to share, to learn from ... You never really get it that way again.

"It," I asked, what is "it?" "Friendships—not people that you socialize with, but people you trust. Mutual respect. We valued those relationships and we protected them."

The work group is a source of primary relationships in our adult lives. The group process and supervisory model must address both the work with participating families and the needs of the program family—its emotional themes and issues—so that the work group can be an ongoing source of support for personal as well as professional growth.

Respectful processes for change

It has been said that excellence is the passionate commitment to a single perspective. Genius is a passionate commitment to the integration of multiple perspectives. Wisdom is the passionate commitment to the *process* of taking multiple perspectives, including respecting the time frame necessary to ecologically incorporate change (Dilts, 1991). Wise leadership of a family/infant program, then, includes respecting the time frame staff require to incorporate change. We know from the research literature on families that healthy families anticipate stress and plan accordingly. It is not that they don't have stress and conflict, but rather that they have a process to count on to deal with it. The same thing applies to work families: during times of stress and change, we must consciously construct *special scaffolding* to support ourselves through the difficulties ahead.

Carl Dunst, Angela Deal, and Carol Trivette, and their colleagues at the Family Infant Program in Morganton, North Carolina have much to teach us about this process. Wise leaders that they are, they built into their program's structure a gradual process to slowly, yet systematically, develop and implement the IFSP (Individualized Family Service Plan) process. They began with two providers and asked each provider to

(Continued after insert)

find a family to be their partner. They met on a weekly basis to share ideas and experiences. Two more providers and parents were added until the group reached eight. Then a new group began the process. This model was used over a one-year period to bring on board all 25 staff members. The groups met for a second year, while working through the model.

Now the Family Infant Program is involved in the next wave of program development and have begun weekly meetings again. Angela says:

> This really works for us. The agenda is different than other meetings. We all know that we are finding our way. We talk about the ups and downs and how it feels. We keep groups at eight or under, and mix experienced and new staff. Each group has a designated team leader who meets with us on a regular basis in a leaders' group.

It's a respectful process, one that incorporates the time, support, and validation needed for change.

Supportive scaffolding in a research/intervention initiative

For the past two years, I have had the opportunity to collaborate with Heidelise Als in a longitudinal study of the effectiveness of developmentally supportive, family-centered NICU practices (Als, 1989). This study has two components: an Experimental component and an Organizational Structures component. At times, we refer to the second part of the Institute as the Organizational Struggles component, for institutional change is a complex, demanding process deserving of the same kind of special support and scaffolding as individual change. Originally conceived of as a qualitative evaluation of the process of implementation, the Organizational Structures component has become an essential ingredient of the intervention model itself.

Every six months (an effective interval for consultation), each neonatal unit in the research institute is provided with a two-and-one-half-day on-site consultation consisting of a series of one-hour individual interviews with members of the research team and with their colleagues on the unit and a half-day feedback session. The interviews, now labelled Reflective Process Interviews, allow each person an uninterrupted hour to be heard, to share his or her experiences over the past six months, to reflect on his or her role and the often strong emotions which accompany such intense and demanding work, and to consider the themes and issues which he or she sees the unit and the research team experiencing. Each team selects other colleagues to be interviewed as part of the documentation of the process of each site, thus bringing parents, neonatologists, nurse managers, staff nurses, social workers, respiratory therapists, and others into a common process. After the interviews are completed, a half-day feedback session is provided for the research team and, over time, for unit colleagues as well. The session provides an opportunity for: feedback on common themes and issues; description of the organizational dynamics of the site; reflection upon where the team is now in relation to where it was six months ago; problem solving and goal setting for the next time period; and team building and support. The consultation requires a blending of knowledge of NICU organization and process, organizational development, systems and change theory, and appropriate interviewing approaches. Overall, this process provides the research project not only with a rich narrative description of the process of model implementation but also with ongoing support and consultation. We have come to see this opportunity to slow the process down, to examine and articulate it, to problem solve and plan, to reflect and renew, as an absolutely essential feature of the process of change in the NICU. Like infants, we need to build into our adult world cycles of rest and activity, to sustain our work over the long haul.

Whether the process be implementing the Individualized Family Service Plan in early intervention, pioneering new ways of working with parents and infants, or rethinking neonatal nursing practices, the task is always the same. The task is human development (Baizerman, 1991). And for this precious task we must build around ourselves supportive processes as dependable as gravity, processes which hold and contain us, and which renew and launch us back again.

References

Als, H. 1989. National Collaborative Research Institute for Early Childhood Intervention: Family-focused Developmental Care and Intervention for the Very Low Birthweight Preterm Infant at High Risk for Severe Medical Complications and Developmental Disabilities.

Baizerman, M. 1991. Musings with Mike. *Child and Youth Care Forum* Vol. XX, No. 3.

Dilts, R. 1991. *Tools for Dreamers: Strategies for Creativity.* Cupertino, CA: META Publications.

Finding Common Ground: Facilitating a Therapeutic Group for Diverse Parents of Young, Disturbed Children

by

Lesley Koplow, C.S.W.

Eleven parents sat on sofas and chairs in the carpeted room, the awkward silence of settling in broken by the drip-drop of the automatic coffee maker and the crash of plastic toddler toys being knocked from the shelf by the two toddlers in attendance. We knew something about the women who sat waiting for a beginning. We had taken detailed histories on each of their families before admitting their children to our therapeutic nursery.

Rosa, the woman on my left, was the Dominican born mother of three girls, the youngest of whom was three years old and autistic. Rosa was bilingual and bicultural, eagerly accepting our invitation for daily participation in her daugher's treatment setting, as this was compatible with her belief that pre-school children were too young to be in school without their parents.

Next to Rosa sat Karen, the wife of a Wall Street executive; Karen came from an Irish Catholic family as did her husband. Karen's stylish, expensive clothing sharply contrasted with Rosa's non-descript apparel. She sat tapping her fingers impatiently, having already informed me that she could not possibly be involved on a weekly basis. She was angry that her young son's violent behavior had brought her to "a place like this."

The next mother, Wendy, sat slumped into one side of the grey sofa. Wendy was a large, pasty looking New York-born Puerto Rican woman, here because preventive services made her attendance mandatory if she wished to retain custody of her four children. Her two- and three-year-old daughters each showed symptoms of Post-Traumatic Stress Disorder. There was a long history of family violence.

On Wendy's right sat a petite, Black woman named Tina. Tina was the guardian of her developmentally and emotionally paralyzed niece who had witnessed her mother being stabbed to death in a fight involving drugs.

To Tina's right sat Donna, an out-of-work actress and the mother of a four-year-old boy with a Separation Anxiety Disorder. Donna reported that her son was "the only reason" that her marriage remained intact. Donna's Italian family owned a house in a pleasant neighborhood in another borough, and would transport their child by car each day.

Beside Donna sat Frances. Frances was a large, African-American woman who was the custodian of her three-year-old grand-nephew who had been born crack addicted and had lived on the street with his mother until coming into Frances' care at age 7 months. Frances also had custody of her nine-year-old granddaughter, and considered herself to be the "only fit mother" in her family. Yet, two of her own children were drug involved, and three-year-old Michael had a Reactive Attachment Disorder, seemingly having lacked the opportunity to attach.

Beside Frances sat Julie, the mother of a three-year-old boy with a Pervasive Developmental Disorder. Children with P.D.D. have an atypical developmental pattern and often show autistic features. During the family interview, Julie spoke of her sadness at not being able to enroll her son in the Jewish day school that she and her husband had chosen before realizing Avi's difficulties. Julie had a background in education, and was particularly concerned about her son's academic learning.

And then there was Veronica at the other end of the couch, sitting leaning her head into her hands. A tall, African-American woman and single mother of the two toddlers in the room, Veronica appeared depleted by the task of caring for her three children, the oldest of whom was severely aphasic. Veronica reported feeling rage at her middle child, her only boy. The children's father had deserted Veronica three months earlier when he "decided he loved crack more than he loved his children."

Ellen sat on a straight chair next to Veronica, holding out her hands to Veronica's children when they walked by. This Black, Georgia-born, 70-year-old great-grandmother was the sole guardian of two great-grandchildren with Pervasive Developmental Disorders. Yet, Ellen still had enough energy to engage other needy children.

My co-worker and I sat collecting ourselves, feeling both challenged and overwhelmed. This group needed common ground, but we did not want to simply provide it by introducing an agenda of topics and assuming an educative role. In our experience, "knowing better" did not always result in "doing better". Indeed, an educative approach often increased parent-child conflict as the parent became flooded with guilt about continuing to act in ways that had now been deemed inappropriate.

Histories indicated that the central parental tasks of providing nurture, authority, and interpretation of the world (Galinsky, 1987) were compromised in some of the parents, perhaps because of their own "forgotten" childhood traumas (Fraiberg, 1980). In some cases, parental roles had been made more complex due to early trauma suffered by the children themselves. In other cases, the children's organic differences had rendered them unable to respond to the usual parental overtures, leaving the parents bereft of the child they wished to love (Solnit, 1961).

Selma Fraiberg's work taught us that parents who are able to connect to their own childhood affects are more likely to empathize with their children and less likely to act out in abusive ways. Thus, we needed to provide a containing, therapeutic environment, a "potential space" where connections could be made (Winnicott, 1965). These included connections between ourselves and the group members, connections between one group member and the other, and connections between each group member's experience of her child in the present and her memories of the affects and experiences of a childhood past. We began with the premise that strengthening these

connections would help parents be more available to their own children.

How were we to build these connections, given the disparity of cultures and educational backgrounds of group members? How would we proceed with people who did not know the language of therapy; who were here only because their young children were so socially and emotionally disabled that they could not function in a group of more than six children? How would we proceed with people who were looking for answers but did not perceive them as coming from within, but hoped desperately that early intervention would repair their children in magical ways?

I began by introducing myself and my co-worker, and asking group members to introduce themselves. I then made some remarks about the group's orientation, which was followed by some initial process:

"We have 12 children in our program," I began. "Each one is here for a different reason. Each child comes from a different part of the city, and brings with him a different family history and his own customs and culture. Even though the kids are so little, we try to help them stay connected to where they come from, but we also try to help them find common ground with one another. Even though some of them can't use words yet, we ask them to find a way to communicate so that they don't end up feeling alone. That's also the reason we have this group—So that parents don't end up feeling alone with a child who's having trouble. We want the group to be a comfortable place where people can feel connected to where they come from, so we need to find a common language to talk about these feelings of connections."

Silence, but only for a moment.

"Well, I've had a lot of experience with this," Donna said with authority. "I've been in other parent groups and it's always the same. It dwindles down to a few committed parents. Most people just don't care. I mean, they just don't care about their own kids! It's amazing." She slapped her knee dramatically.

Frances picked up where Donna left off.

"You got that right. These young mothers today don't have no kind of responsibility! They just keep on havin' babies and then when it comes time to really deal with it, they ain't there."

"Just look at the paper!" Wendy commanded from her place on the sofa. "Every single day you read about some mother killing their own kid. Now *those* are the people who need to come to a place like this. It made me feel terrible putting my kids here, saying that they were emotionally disturbed. I mean, I like the school and everything, but I don't agree with that. I had some problems in the past, I don't deny it, but I don't think the girls are that bad.

"Well, you think that's bad," Karen interrupted. "Marcus was diagnosed emotionally disturbed before he was even two. They told us, 'We have good news and bad news. Marcus is intellectually gifted, but we think he's emotionally disturbed.' Now how can a child not even two years old be emotionally disturbed?"

"My parents ask me the same thing," Julie responded. "They just don't believe there is anything really wrong with Avi. They say I was something of a loner when I was a child, but I outgrew it."

"Do you remember?" I ask quickly.

Julie shook her head.

"Does anyone remember being the age your child is now?" my co-therapist followed up.

"My Lord. That was a long time ago," mused Ellen, shaking her head. She brushed her slacks as she spoke, as if to make sure that there was no dust clinging to her from times long past.

Veronica looked up as though to assess whether we had taken leave of our senses. "Don't remember nothin' about bein' small," she mumbled. "These little people ain't gonna remember nothin' 'bout what we say now when they're grown, so ....." She shrugged, as though to ask what the point could be of all this talk. As it turned out, that would be the last comment Veronica would make for weeks, her silence punctuated by shrugs and a refrain of "I don't remember."

"I remember plenty," Wendy took over with a booming voice. "I remember having to sit perfectly still in a chair in the corner of the kitchen. My mother said, 'Don't you move' with that look in her eye, and I knew she'd beat the crap out of me if I moved an inch."

Julie, Karen and Tina shifted with discomfort. Veronica, Donna and Frances looked interested.

"Do you remember how you felt?" I asked gently.

Wendy looked blank. "I'm sure I didn't like it. No kid likes to sit still for too long."

"Not me," chimed Rosa. "I had a beautiful mother. She give me everything. I sleep with that woman til I had 17 years. Aye. I don't want to remember that beautiful life."

There was a lot to sort out here. Already, there were emerging themes. "Bad", irresponsible parents "out there": versus the "good", idealized parents "in here". There was denial of the rage and guilt about the "not that bad" children in the other room, yet in so many ways the women seemed paralyzed by these unowned feelings. Connections to experiences of childhood were tenuous, non-existent, idealized, or remembered without feeling. Yet, we considered these connections to be essential precursors to the formation of healthy parent-child relationships. In addition, the memory of childhood was a potentially common ground for an otherwise disparate group. There were group members who had been born in other countries and group members who had never left New York, but childhood was somewhere everyone had been.

We proceeded in the coming weeks and months to conceptualize our clinical task as two-fold: the tasks of inviting and containing. We invited members to remember

their pasts, and to consider their own pasts as relevant to their children's present. We extended permission for the memories to include the feelings experienced (Fraiberg, 1980). And perhaps most importantly, we acted to contain the material by intepreting it in a developmental context, and by returning week after week, thereby conveying our ability to survive the feelings expressed. As each group participant also had an individual session weekly, we were confident that threatening material could be followed up with more fragile members. As one parent group each month included the children, we were able to observe parent-child interaction within the group milieu and to see if individual and group parent work affected the ways that parents actually related to their children.

Parent-child groups were directed by the staff and included a group sing and an activity designed to promote reciprocity between parents and children. On the other hand, weekly parent groups were open-ended and process oriented. Typically, it was one of the more fragile members who brought up the most fruitful topics. These often began as "out there" topics, issues that were perceived as external and could then be re-interpreted in terms of internal, or owned experience. The following piece of mid-year process will provide an illustration:

Frances—Anyone seen that headline in the *Daily News* this morning? A mother took her three-year-old child and tried to put him in the oven. When he climbed out, she beat him to death.

Expressions of horror from the group.

Frances—Now sometimes I do get angry at Michael and I yell "if you don't stop that I'll kill you", but I know I wouldn't really go that far. Somethin' would stop me 'fore I got that far.

Donna—Of course not. Because he's yours. I mean, even though he didn't come from you, he's been yours since he was a babe. Look. You and I are decent people. With my little Ronnie, I rage and yell and threaten him and sometimes I tap his little hiney, but then I see that little face and I melt. I just turn around and give him what he wants. One minute I want to kill him and the next minute he has me wrapped around his little finger.

Therapist—Was there something in the article about the kid wanting something before the mother snapped?

Tina—He wanted jelly bread. The kid just wanted jelly bread. The first time Rhonda asks me for some special kind of food, I'll jump up to make it—I'll be so happy to hear her ask.

Therapist—So for you, it will feel good to hear Rhonda ask for what she wants.

Tina—I'll get it for her no matter what time of the day.

Therapist—You think your mother felt like that about you and your brothers and sisters asking for what you wanted?

Tina—Well, there was 10 of us, you know. Sometimes there wouldn't be enough to go around.

Frances—*That's like when I was comin' up. Eight kids* fighting over one piece of bread. You want it, you better fight else it be gone.

Therapist—You think the mother's losing it had something to do with not having enough to give the child?

Wendy—That's no excuse. She could have took time out to explain to the child. I mean, many times GeeGee and Belinda want something and I just plain don't have the money to go out and get it. That's the way it is. Jesus. I don't go killing them.

Frances—It's one thing to say "I'm gonna kill you"—It's another thing to go and do it.

Therapist—Maybe feeling like you don't have enough to give can be a very disturbing feeling.

Silence.

Veronica—Yesterday I been on the subway and Tim start screamin' for no reason. I told him to shut up, but he just kept doin' it, and I said "stop or I'll kill you" and started beatin' his butt. Lady cross the way turn around and tell me she gonna call BCW. (Child Welfare)

Rosa—Good for you. You beat that boy too much.

Veronica glared at Rosa, but clearly took pleasure in the scolding.

Therapist—Why did you want to spank Tim?

Veronica—'Cause he wouldn't stop. And all those people be lookin' at me like ... "you can't even control your child." I didn't even put my hand on him 'fore she said that.

Tina—What did you say to her?

Veronica—Told her mind her business. I'll kill her instead. She don't know what Tim be like sometimes.

Chuckles from the group.

Julie—It's really hard to have people looking at you and judging you. I can't say I never hit Avi. One time we were walking on a busy sidewalk and he just sat down and refused to move and started screaming when I pulled him. I slapped him, not because I thought it would do him any good, but I was just so angry that he was putting me in that position.

Veronica looked at Julie, seemingly amazed that Julie too sometimes felt embarrassed by her child's behavior.

Donna—Yeah. One minute people are looking at you like you're the madonna who brought this adorable little child into the world. The next minute they look at you like you're to blame for the existence of that little monster tearing up the grocery store aisle.

Everyone nods at this and there is silence.

Therapist—I'm thinking about both Frances and Veronica telling stories about threatening kids with "I'm gonna kill you" and the newspaper story being scary because that mother lost the boundary between feeling like doing something and actually doing it. I think most of the kids here have trouble with that boundary between feeling

and doing and tend to take things pretty literally. A threat may be really scary for them. Does anyone here remember their own experience of being threatened as a child, and how you understood it?

Silence.

Therapist—Veronica?

Veronica smiles a false smile and shrugs.

Donna—There was no problem of misunderstanding in my family. My mother would tell me she would beat the shit out of me and she did.

Wendy—Ummm. No problem there.

Frances—Well, you just put me in mind of something. I don't know if this is exactly what you mean ... Anyway, we lived out in Far Rockaway when I was comin' up. And I must have been six or seven ... there was this big storm, like what you call a flash flood or something. While we were at school, it got real bad. I mean, there was so much water, the street was like a river and no cars could pass, so they let out school early and took us home in row boats.

Sounds of astonishment from the group. They are riveted.

Frances—I felt like, wow! This is dangerous. I don't know. Then a teen-age girl who lived around my way tells me, "we gonna die". That's all I needed to hear. I sat in that boat with all that water splashin' up on me and I didn't know what was happening to me. I couldn't move or nothing, I was so scared. ...

Rosa—(anxiously) What happened? Your mother was home?

Frances—Yeah, she was home. But, I mean, I was shakin' ... First all that water, and then them words ...

Therapist—Sounds like those words were powerful coming from someone older than you ...

Frances— Yeah. I hadn't thought about that in a long time. ... I guess Michael might really be scared when I tell him things! I guess I better watch what I say.

The issues arising in this session were fundamental to the process of parenting young children. Parents' idealized images of their children were often dashed by the children's difficult behavior, causing deep embarrassment for some mothers and devaluing of the children and of themselves for others. There was the question of what constituted danger for a child, and initially, a denial of the power of their own ominous threats. There was clearly connection to material involving feelings of helplessness that come from being unable to satisfy a child, yet these helpless feelings were not owned. There was a deep confusion between "feeling like" and "doing" which prohibited parents from experiencing their emotional reactions to the frustrations of parenting and paradoxically left them at greater risk of acting out.

All of these issues were able to find expression through group process that involved parent-initiated topics, reactive material from other parents, and the therapist's reflective and interpretive statements. Sharing feelings about taboo subjects seemed to work to diminish isolation and increase participation. Frances' childhood memory may have been a group milestone as she was able to feel the feelings that the long ago experience had engendered and to allow others to empathize with her. This led her to conclude that her nephew perhaps felt afraid of her threats and required empathy from her.

The next piece of process shows an evolution in the participant's ability to connect spontaneously to affective memories and to see their implications for their current roles as parents and caregivers:

Rosa—What can we talk about today? Please, talk about something nice. No stories from the paper. Oh my God.

Therapist—Have you been thinking about something we talked about recently?

Rosa—No. I think only about my own beautiful daughters.

Wendy rolls her eyes as she often did when Rosa spoke.

Ellen—Well I have been thinking about something.

Everyone looked at Ellen, who rarely contributed.

Ellen—It was something that came to mind when you (points at Frances) told that story about the boat and the big girl tellin' you you would die. I've been remembering ... You know, I came up in Georgia, in the woods you might say. Little house with dirt floors and nowhere near no other houses. You know, my mama died when I was about 5 years old and my Daddy was, ... no good after that ... He drank so much ...

None of us, including the therapists, had ever heard Ellen's story. The whole group seemed to hold its breath, waiting for her to continue.

Ellen—But I did have a grandmother. Every once in a while, in the summertime, my Daddy would take a few of us over to her house and leave us a while. So, I passed the summer with my grandmama, her hangin' out the wash and talkin' over the fence to a neighbor. I was playin' around her, not really listenin' but I heard my grandmama say these words—"There's a dead cat on the line." So, I ran all the way from where the clothes line started to where it finished and I didn't see no kind of cat, dead or alive. So I checked again and again, thinkin' it must be there if she said it was there ... Finally, I ran back to where she was talkin' and I said, "Grandma! I looked ... There ain't no dead cat on the line!" She turned around and slapped me so hard I went flyin'.

Ellen looked tearful at this part.

Therapist—Did you cry?

Ellen—I didn't cry. I was just sort of ... in shock. I didn't know what I had done ... I just wanted to see what a dead cat on the line was, 'cause it sounded so awful ... Then it wasn't there after all and I just wanted to tell her. I guess she really hurt my feelings. ....

Therapist—First the words scared you and then the slap hurt your feelings ...

Ellen—Can you imagine? That must have happened about

63 years ago and I remember after all that time.

Therapist—Did you ever ask her about it when you got older?

Ellen shook her head.

Donna—(wiping her eyes dramatically) That really makes me feel terrible. Like every rotten thing I say to Ronnie he'll remember for the rest of his life.

Ellen—Makes me wonder about Melissa (drug-addicted granddaughter raised by Ellen). Makes me wonder if she felt so bad about some of the things I said to her when she was comin' up . . .

Veronica—Tim don't understand what I say anyhow, so . . .

Julie—Well, Avi doesn't always understand either. But it seems like he just doesn't care sometimes. (Julie sounded sad).

Tina—You never know though. Probably Ellen's grandmother thought, "Well she don't even care" since she didn't cry or anything when she smacked her. . . .

Discussion

We have been slow to allow therapeutic principles to inform our group work with parents, and typically approach parenting as a body of information that can be taught. These bits of parent group process highlight the evolution that can occur when parent groups are open-ended and process-oriented, and when they value affect-laden material.

The process included here was selected for content and technique that seemed to illustrate issues salient to this population of parents. Over time, groups included many segments such as those quoted here, as well as less focused, seemingly tangential discussion and dramatic arguments between participants. Indeed, my co-worker and I felt the group had truly become therapeutic for the members when they chose to give voice to a conflict that had developed between a small group of parents during the group hour "so that no one would get hurt outside."

Naturally, some parents found the group experience difficult. Of the eleven parents whose children were in the program at the time of writing, eight attended regularly, one never attended unless the children were present, and two "played peek-a-boo" with the group. These parents would participate and then go into hiding for some weeks before emerging again. Mandatory monthly parent-child groups helped ambivalent parents to come back to a less threatening milieu. These monthly groups became an important part of our treatment program, as they allowed parents to experience their emotionally troubled children in a supportive group atmosphere in which they could more easily be seen as productive and successful. While early parent groups featured many "I'm a good parent" proclamations that seemed at odds with actual parenting behavior, later, parents seemed to have less need to compensate with self praise, and showed more "I'm a good parent" action through the parent-child groups.

The following premises, emerging from parent group process described above, may be useful to facilitators of diverse groups of parents:

1) **Inviting group members to remember their own early experiences and to remember the feelings engendered by these experiences may provide connective tissue for isolated people.** Parents who begin to recognize the child in one another and in themselves may show an increased capacity for empathy with their own children.

2) **Inviting group members to explore and express ambivalence about their children may lessen the danger that parents will feel obliged to present a "good mother" image** to facilitators and to parents from other cultures and ethnic groups, thereby leaving troublesome material out of group dialogue.

3) **Valuing contributions of less educated parents may result in greater participation by this group which may offer rich material.** Facilitators should welcome material given in first languages and in dialects when possible as this language is likely to be evocative of early memories and feelings.

4) **Communicating the facilitator's ability to contain threatening material may be accomplished by maintaining a neutral stance and by referring to past group process, thus demonstrating the therapist's capacity to "hold" material.** For example, the therapist's neutral stance may have allowed Veronica to disclose her experience of being threatened with a child abuse report. The therapist may then have referred to this material in future sessions so that Veronica knows that she was heard and did not frighten the therapist away with difficult content.

Open-ended groups of diverse parents are likely to generate some intense and difficult material. Participants should be seen individually as well so that issues can be followed up on each member's level. When individual therapy is precluded by lack of resources, programs may want to run weekly parent-child activity groups as a primary form of parent intervention and supplement these with monthly discussion groups where participants have an opportunity to reflect on interactions between their children and themselves.

Finally, group therapists must attend to their own countertransferences to group process in order to convey a containing, therapeutic presence. If we want to communicate that the ground of the psychological world is safe to walk on, we must feel safe enough to make the journey.

References

Fraiberg, Adelson and Shapiro. "Ghosts in the Nursery: A Psychoanalytic Approach to the Problems of Impaired Infant-Mother Relationships". *Clinical Studies in Infant Mental Health*. N.Y.: Basic Books, 1980.

Galinsky, Ellen. *The Six Stages of Parenthood*. MA: Addison Wesley, 1987.

Solnit, A. and Stark, M.H. "Mourning the Birth of a Defective Child." *Psychoanalytic Study of the Child*. 16: 523-537, 1961.

Winnicott, D.W. *The Maturational Processes and the Facilitating Environment*. N.Y.: International University Press, 1965.

The Long Aftermath: Ethical Dilemmas in Resource Allocation Posed by the Care of Medically Fragile Young Children

by

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Ethical dilemmas in health care have become a veritable growth industry during the past decade. The discovery of technologies that redefine the beginnings and endings of life and the unanticipated costs associated with dazzling new procedures have left us both awed and confused. While the study of bioethics has become an urgent new subspecialty in the medical arena, there has been insufficient attention to ethical analyses among the majority of disciplines providing early intervention services to infants and toddlers with disabilities.

Ethical analysis is often incorrectly perceived as either an esoteric flight into the outer reaches of philosophy or as a set of procedures applied to people in the final stages of life. Rational application of ethical principles is, in fact, the foundation of both morally consistent public policy and individual behavior. Ethical analysis can assist us to ensure that particular policies are congruent with the principles to which we wish to subscribe.

The present political and economic environment demands that we undertake an assessment of the philosophical constructs that guide decisionmaking. Before we can make appropriate judgments about such compelling issues as the extent to which society should provide adequate health care for its citizens or the nature and breadth of services that should be available to people with disabilities, there must be a process of collective introspection regarding the meaning of our core ethical values.

This essay will review major ethical principles that are the foundation of health care decisionmaking and then consider the population of extremely premature infants and home care for medically fragile children as phenomena that pose ethical dilemmas for families, professionals and the larger society.

Major ethical principles

Ethical theory is a summary of cultural and religious tradition and a vehicle to provide a moral framework based on that tradition. It is a source of guidance sufficiently general in its application to transcend the idiosyncracies of particular times and events, yet sufficiently specific to offer boundaries and parameters for decisionmaking. Ethical theories are generally classified as either **teleological** or **deontological.**

Teleogism is utilitarian in nature, designating ethical decisions as those that produce the greatest balance of good over evil for the group concerned. Teleogism provides the philosophical basis for such economically oriented approaches as cost-benefit analysis and cost-effectiveness analysis. Critics of utilitarianism have assailed the assumption that all "goods" can be measured and weighed comparatively. It is exceedingly problematic, for example, to determine a "unit of happiness" that can be used in meaningful calculations of comparative benefit.

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Deontology is an approach that features adherence to absolute principles without consideration of comparative consequences. Major deontological principles that have guided health care decisionmaking include: *autonomy, beneficence,* and *justice.* Robert Veatch (1986) further divided these principles into those that are patient-centered and those that are social-centered. These principles form the bases of considerable discussion in the bioethical literature.

Autonomy is the foundation for patient self-determination and the philosophical cornerstone of individual definitions of quality of life. However, the principle of autonomy is of little help when dealing with newborns and very young children. They are regarded as "noncompetent decisionmakers" since they have never possessed the ability to engage in autonomous thinking. The increase in technology-sustained, marginally viable infants, as well as the chronically ill elderly, has posed new challenges to surrogate and proxy decisionmakers.

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Beneficence is a principle that emphasizes both individual and societal levels of analysis. According to Veatch, patient-centered beneficence, at the individual level, requires that the actions of health care providers benefit the patient. The concept of patient-centered beneficence is taken from the Hippocratic Oath, which admonishes the physician that the primary duty of intervention is to benefit the patient to the best of the physician's ability and judgment. Full beneficence, at the societal level, involves consideration of the benefits and harm of a health care decision to all parties, not only the patient. Full beneficence requires health planners to devise policies for the just distribution of health care resources.

Justice in the context of health care requires that "resources should be distributed to provide all with an equal opportunity for health" (Veatch). Justice emphasizes equity or fairness in distribution of resources, with an acknowledgment of some form of egalitarianism. For a health care system to be just, there must be harmony between the two components of beneficence: Treatments should benefit the patient, but should not consume such extensive resources that other people are denied appropriate treatment. The disproportionate consumption of resources by the medically fragile population may represent a challenge to the construct of justice.

The long aftermath of medical intervention with extremely premature infants

Discussions about the ethical allocation of health care resources too often fail to consider the long-term implications of treatment decisions. Yet those of us who work with children and their families know that it is the long aftermath of medical intervention that raises the troubling ethical, fiscal, psychosocial and public policy dilemmas. A central tenet of public policy in this post-Baby Doe era features the desirability of home care for even the most medically fragile and technology dependent children. But at times it has appeared that discussion of this population has focused excessively on institutional process, determination of methodology to calculate cost-effectiveness, and the nuances of payment systems. This focus has camouflaged what should be our central ethical questions: What ethical principles have been employed to devise a comprehensive care system for medically fragile children and their families? Are we on the right course? What do our present policies mean for the future?

To understand ethical issues surrounding the long aftermath, we must focus on both the emergence of our current population of extremely premature infants and the growth of the home care movement.

The changing profile of prematurity

Care of the premature baby has improved with such rapidity during the past 15 years that heroic measures of the mid-1970s are simply routine interventions today. Follow-up studies (Chaikind and Corman, 1990; Groggard, et. al. 1990; Eilers, et. al., 1986; McCormick, et. al., 1990) generally confirm that children formerly on the edge of viability—those with birthweights in the 1200 to 1500 gram category with gestational ages of about 30 weeks—are less likely than their earlier cohorts to experience mortality and significant disability. These children of conventional low birthweight (under 2500 grams but over 800 grams) constitute about 7% of live births annually (Richmond, 1990).

Now we are seeing a new generation of premature infants, who are the recipients of the latest advances in high technology in neonatal medicine. These babies are on the frontier of extrauterine viability with birth birthweights in the 500 to 750 gram range, gestational ages of 24 to 25 weeks and often surviving with a range of disorders. While they represent less than 1% of annual live births (Hack and Fanaroff, 1989), their often complex ongoing care has required a significant utilization of both public and private resources. On the one hand, clinical profiles of children who have done exceedingly well despite grim prognoses can confirm the benefits of aggressive neonatal intervention. On the other hand, the possibilities of such secondary diagnoses as chronic lung disease, cerebral palsy, mental retardation and sensory impairment underscore the range of consequences that can be associated with innovation.

The emergence of medically fragile/high technology children coincided with two significant issues for the health care community: 1) The recognition of the finitude of health care resources; 2) The demand for an alternative to the subspecialized, impersonal world of the hospital for children with both acute and chronic conditions. The prospect of children experiencing extended hospitalization was perceived as a failure of the human services system to respond to the challenges of medicine (Department of Health and Human Services, 1982) as well as a source of potential fiscal catastrophe.

The growth of the pediatric home care movement

In response to the advocacy efforts of the family of a ventilator-dependent child, Katie Beckett of Iowa, President Reagan requested that the federal health establishment review how home care services are provided to chronically ill children. In 1981, new federal legislation created a Medical Assistance waiver program that encouraged the states to create model programs which would encourage home care alternatives for children who would otherwise be hospitalized and which would reduce overall costs.

Home care of medically complex children has been characterized by three assumptions: 1) That it is beneficial to the family; 2) That it is beneficial to the medically fragile child; 3) That it is cost-effective to the family and the third party payor. Let's review these assumptions.

It is exceedingly difficult to quantify the impact of raising a medically fragile child on the family. Spiritual and material resources, family priorities, social support, pre-existing marital and familial stressors, and eligibility

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for home nursing and related services can affect the long-term impact of caring for the child. Yet despite these idiosyncracies there are consistent themes that resound in the literature.

In an early analysis Burr, et. al. (1983) wrote that families of medically fragile children at home reported loss of privacy, curtailment of sibling activities and abandonment of plans to have subsequent children. Kohrman (1991) describes psychological consequences of caring for a medically complex person at home which include anxiety about the patient's survival and the competence of the family to provide adequate care; role confusion as family members assume a quasi-professional relationship with the child; exhaustion; endlessness; and guilt. Johnson (1987) and Byers and Fabian (1988) discuss the effect of stress, burden of care, social isolation and social withdrawal as well as a sense of powerlessness that can accompany frequent rehospitalization.

Schreiner, et. al. (1987) have warned that accidental deaths at home may create a sense of family guilt and responsibility. Stein (1987) has written about the multitude of stressors placed on families. Bancalori (1987) has advocated home care under only the most optimal conditions and Quint, et. al. (1990) conclude that the ongoing care places a substantial burden on families.

The data are not all gloomy. Such organizations as the Association for the Care of Children's Health have sponsored conferences during the past decade at which parents have spoken about the beneficial impact of home care, the unexpected developmental gains made by their children once they were at home and a positive reassessment of family priorities and values. In situations where the overall health of the child improves, and particularly when a technology-dependent child becomes technology-free, the family can experience a process of renormalization and psychological repair.

It is clearly too early to advance any long-term conclusions regarding the impact of home care on families since this is a relatively recent experience. It is, therefore, also too early to endorse the increasingly held conviction that home care is the wisest alternative for families of medically fragile children. There has been insufficient time for the long-term impact of transferring site of care from the hospital to home to be understood. However, this ambiguity has not altered the adoption of home care as the policy of preference within the health care community. The fears expressed by those who have urged caution in the popularization of home care have been eclipsed by policies that essentially mandate home care whenever it is remotely feasible (Stein, 1987).

The second assumption of home care, that it is beneficial to the child, is also complicated to analyze. Most follow-up studies of premature infants have focused on the neurodevelopmental outcome of children with varying birthweights, gestational ages or clinical profiles. Site of care is not generally the emphasis of this research. Simply because a child is of low birthweight does not mean that he is medically fragile. But because there is a correlation between medical fragility and low birthweight it is important to determine the developmental prognosis for children born at the edge of viability.

The challenge in attempting to assess developmental prognosis for the new generation of surviving prematures is that longitudinal data are available only from the considerably more intact babies who have survived prematurity in the 1970s. The follow-up studies on those 1000 to 1500 gram children, while encouraging, may have limited generalizability to the children who are now graduates of neonatal intensive care. Yet even these relatively positive studies confirm that children of conventional low birthweight are at risk for compromised outcome (McCormick, 1989; Eilers, et. al., 1986).

The few follow-up studies on the smallest survivors offer relatively grim scenarios. In 1986 Hack and Faranoff studied a sample of extremely low birthweight children and found a survival rate of 33.5%; of those surviving, 31% were left with significant enduring neurodevelopmental handicaps. In a 1989 article the

same authors compared the outcomes of a cohort of babies born with birthweights below 750 grams between 1982 and 1985 with a similar cohort born between 1984 and 1988. They found similar rates of mortality (20%) during the two periods. Between 22% and 50% of the children in each group had moderate to severe impairment. The rate of handicaps reported in these studies suggests that the decrease in morbidity observed in successive cohorts of the conventional low birthweight basbies may not be expectable in this population.

The third assumption of the home care movement, that home care is less costly than extended hospitalization for third party payors, does seem warranted. The costs of NICU care for very low birthweight infants and hospital care for medically complex children have been well documented (Stahlman, 1984; Hernandez, Offuit and Butterfield, 1986; Hack and Faranoff, 1986; Fischer and Stevenson, 1987; Stein, 1986; Sweeney, 1986). Even in the few pediatric "step-down" facilities that are capable of providing high technology care, annual costs can exceed $180,000 per child (Battle, 1987). In contrast, annual costs to Medicaid of home care for a ventilator-dependent child were found to be $109,836, a savings of $79,000 over hospital care; home care for an oxygen-dependent child cost $83,000 less per year than hospital care (Fields, et. al., 1991).

It is more important to note, however, that calculations of home care cost savings generally limit their focus to comparison with inpatient hospital costs. They do not deal with expenses associated with rehospitalization and follow-up therapies; cost shifting to families; and the effect of the child's specialized needs on community resources.

Ethical dilemmas revisited

The limits of current knowledge about expectable outcomes for very low birthweight premature and medically fragile children challenge our ability to make decisions about care in accordance with sound ethical judgments. The principles of autonomy, beneficence, and justice do not offer clear guidelines to families and decisionmakers. Families encounter a society that lavishes fiscal resouces on their children's *initial* treatment but then delivers them to a social system unprepared to deal with the long aftermath of medical and developmental needs.

Dr. Constance Battle has written:

> It is time that we acknowledge that the interests being served in some cases of heroic intervention are not those of the baby and family but rather of a physician engaged in a great momentary professional challenge ... We must let physicians see the natural and unnatural course of all illness. They should understand that the overwhelming problems of premature babies in the newborn period are only a small part of the story (Battle, 1987, p. 419).

We have arrived at this point because of a collective unwillingness to ensure that the priorities of our health

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care system are grounded in a sound ethical framework. Health care strategies must ensure that technology is used to promote a positive quality of life for the child and family. We must not simply deploy technology in the NICU and be unmindful of its range of long-term consequences.

Families of medically fragile children must be given an array of care options and not simply be expected to provide ongoing care at home. Community-based alternative living units or extended care centers are needed so that there is a comprehensive continuum of alternatives to acute hospitalization. Some families have negotiated part-time home care and part-time specialized foster care arrangements so that family life and priorities can be balanced and activities beyond the care of this child can still be pursued.

It is time that we reject heroism in favor of an anguished reappraisal of the purpose of intervention. There is a need for thoughtful reassessment of the use of medical technology with some of our most fragile babies. On the micro level it is clear that in too many cases the concept of patient-centered beneficence is being violated as the advantages of treatment are outweighed by the physical suffering of children and emotional suffering of families. On the macro level, there is increasing recognition that diversion of resources to this tiny population can be an injustice to the larger number of children who could have been helped by these expenditures (Young and Stevenson, 1990). To deploy technology simply because it exists undermines the application of ethical principles to public policy.

One could argue that reducing efforts to this population is contrary to medical progress. After all, had a similar strategy been adopted 15 years ago we would not have the many healthy, intact survivors of conventional low birthweight who are here today. The availability of such new therapies as artificial surfactant could have a positive impact on outcome. Also, how do we justify reducing efforts when there are survivors who have done remarkably well?

At some point it is our social responsibility to ensure that full beneficence is the hallmark of our health care and social system. Improved access to and availability of prenatal care and increases in funding for such prevention programs as WIC (Women, Infants and Children), Medical Assistance and Head Start may better serve those families who are most vulnerable to experiencing extreme prematurity. Present resources may not enable us to continue to incur the costs associated with aggressive neonatal treatment while attempting to improve the health, educational and social services that are vital to the care of this population as well as the larger population of children. The Oregon experiment is attempting to redirect public expenditures away from high cost/low incidence procedures and bias the system in terms of low cost prevention strategies. We must study the results of this far-reaching strategy.

We live in the midst of a number of technological and social experiments. We are attempting to respond to the profound changes in technology by building public policies that are grounded in consistent ethical principles. However complex the ethical dilemmas before us, we cannot be passive bystanders as we observe the awesome impact of modern medicine. It is our obligation to support families and children, bear witness to their experiences and devise policies that are sensitive and sensible. As we advocate for justice for the newest generation of children with special needs, we should never forget that the moral distribution of social resources must be anchored in the principle of justice for all.

References

Bancalori, E. Care of the infant with prolonged ventilator dependency. *Journal of the American Medical Association 258*(23): 3430-31.

Battle, C.U. (1987). Beyond the nursery door: The obligation to survivors of technology. *Clinics in Perinatology* 14(2): 417-27.

Burr, B., Guyer, B., Todres, D., Abrahams, B. and T. Chiodo. (1983). Home care for children on respirators. *New England Journal of Medicine* 309(21): 319-23.

Byers, J.E. and E.M. Fabian. (1988). The parent drop out syndrome. *Caring* 7(6): 36-38.

Chaikind, S. and H. Corman. (1990). *The Special Education Costs of Low Birthweight Children*. National Bureau of Economic Research, Cambridge, Massachusetts.

Department of Health and Human Services (1982). *Report of the Surgeon General's Workshop on Children with Handicaps and Their Families*. Washington, D.C.: U.S. Government Printing Office. PHS 83-50194.

Eilers, B.L., Desai, N.S., Wilson, M.A. and D. Cunningham. (1986). Classroom performance and social factors of children with birthweights of 1250 grams or less: Follow-up at 5 to 8 years. *Pediatrics* 77(2): 203-8.

Fields, A.I., Rosenblatt, A., Pollack, M.M. and J. Kaufman. (1991). Home care cost-effectiveness for respiratory technology-dependent children. *American Journal of Diseases of Children* 145: 729-33.

Fischer, A.F. and D.K. Stevenson. (1987). The consequences of uncertainty. *Journal of the American Medical Association* 258(14): 1929-31.

Grogaard, J.B., Lindstrom, D., Parker, R.A., Culley, B. and M.T. Stahlman. (1989). Increased survival rate in very low birthwesight infants: No association with increased incidence of handicaps. *Journal of Pediatrics 114*: 839-46.

Hack, M. and A.A. Faranoff. (1986). Special report: Changes in the delivery room care of the extremely small infant: Effects on morbidity and outcome. *New England Journal of Medicine*. 314: 660-664.

Hack, M. and A.A. Fanaroff. (1989) Outcomes of extremely low birthweight infants between 1982 and 1988. *New England Journal of Medicine* 321: 1642-7.

Hernandez, J.A., Offuit, J., and L.J. Butterfield. (1986). The cost of care of the less-than-1000 gram infant. *Clinics in Perinatology*. 13(2) 461-8.

Johnson, D.L. (1987) Possible long-term effects of high technology on the child and family. *Focus on Critical Care* 14(4): 43-50.

Kohrman, A.F. (1991). Psychological issues in Mehlman, M.J. and S.Y. Youngner. *Delivering High Technology Home Care*. New York: Springer Publishing Company.

McCormick, M.C. (1989). Long-term follow-up of infants discharged from neonatal intensive care units. *Journal of the American Medical Association* 261: 1767-72.

McCormick, M.C., Gortmaker, S.L. and A.M. Sobol. (1990). Very low birthweight children: Behavior problems and school difficulty in a national sample. *Journal of Pediatrics* 117: 687-93.

Quint, R.D., Chesterman, E., Crain, L.S., Winkleby, M. and W.T. Boyce. (1990). Home care for ventilator-dependent children *American Journal of Diseases of Children* 144: 1238-41.

Richmond, J. (1990). Low birthweight infants: Can we enhance their development? *Journal of the American Medical Association* 263(22): 3069-70.

Stahlman, M. (1989). Implications of research and high technology for neonatal intensive care. *Journal of the American Medical Association* 261(12): 1791.

Stein, R. (1987) Providing home care for the seriously ill young. *Business and Health* 26-30.

Sweeney, R. (1986). Summary of testimony on catastrophic illness. Secretary of the Department of Health and Human Services' Private/Public Sector Advisory Committee on Catastrophic Illness. Oakland, California.

Veatch, R.M. (1986). DRGs and the ethical allocation of resources. *Hastings Center Report* 16(3): 32-40.

Young, E.W.D. and D.K. Stevenson. (1990). Limiting treatment for extremely premature, low birthweight infants. *American Journal of Diseases of Children* 144: 549-52.

NCCIP: Achievement and Challenge
Remarks upon Receiving the Dolley Madison Award

At each of its biennial National Training Institutes, the National Center for Clinical Infant Programs presents the Dolley Madison Award to an individual who has made an outstanding lifelong contribution to the development and well-being of very young children and their families. The winner of the 1991 Dolley Madison Award is Urie Bronfenbrenner, Professor Emeritus, Department of Human Development and Family Studies, Cornell University. Previous award winners have been Anna Freud, Julius Richmond, Selma Fraiberg, Milton Senn, Lois Barclay Murphy, Reginald S. Lourie, and Sybille Escalona.

The text of Dr. Bronfenbrenner's award reads as follows:

Urie Bronfenbrenner has immeasurably enhanced our understanding of the world of childhood. As is the case with all true innovators, his originality and insights have changed irrevocably the way we think about the world. Even our vocabulary has changed. Now, we speak of the "ecology" of childhood. His wonderfully vivid phrase, "Every child needs someone who is crazy about him" has become part of the working language of Urie's colleagues and of policy makers.

He has rearranged our mental furniture as well, and improved the lighting. He has illuminated the complexity of the interacting systems that influence the child's growth and development, and changed an entire field in the process. Urie has for many years been child psychology's premier synthesizer due to his ability to process huge amounts of data and find signals where others find only noise.

Nor is he solely an academic leader: He is a fully engaged human being, ready to put theory into human practice. Nowhere is his willingness to pitch in and give his brilliant best better reflected than in his role as a founder of the Head Start program. Through that important moment in the history of social policy for children, countless youngsters have been given a better chance to achieve their own potential. Urie has nurtured the talents of many individual students as well, and these have gone on to improve the lives of children and families in a wide variety of professions and settings.

In a sense, we are all Urie's students. Child development researcher, social observer and mentor, advisor of governments, Urie Brontenbrenner inspires us to new worlds of insight and commitment.

Remarks by Urie Bronfenbrenner:

For once, I find myself at a loss for words, and looking about for someone who really fits and deserves the wonderful words you have just heard. And I have found who that is—it's you, my colleagues.

For science is a community of scholars, human service is a community of healers, and you are both. Throughout my professional life, I have aspired to be a member of such a community. So you can understand the special meaning that this occasion has for me. I thank you.

But this is only the first thank-you. There are three more to come. They will be short, but from the heart, and from the head. For I recognize that, although I am *with* you, I am not truly *of* you. I *am* a researcher, and I *was* a working clinician for almost a decade early in my career, but I am no longer. I have, however, tried to keep the faith in other ways. But so have you.

For that reason, I should like to take this brief opportunity to express appreciation for three special ways in which you have sustained and enhanced the well-being of young children in our nation, and of those who care for them. For I am your witness.

The first of your contributions comes closest to home for me. For more years than I care to acknowledge, I have been working on a book manuscript that undertakes to define and to document the unmatched power of *proximal processes and relationships* in human development—unmatched *provided*, (and the proviso is critical), *that such processes occur on a fairly regular basis for extended periods of time.*

What do I mean by proximal processes? I refer to the **emotionally-loaded, reciprocal interaction that takes place between an active, growing human organism and the persons, objects, and symbols in its immediate environment.**

In the book manuscript that I am working on, I show, both demographically and ethnographically, that in today's ecology of children and families, such processes are getting ever shorter shrift. Moreover, this phenomenon is occurring not only among the poor, but in every segment of society, and is particularly pronounced in our own country. Among the so-called developed nations, the United States is leading the way—and by a substantial margin.

In the manuscript, I then proceed to show, on the basis of today's accumulated research, that, in the last analysis, such emotionally-loaded proximal processes account for more of the variation in human competence and character than any other factor, either in the environment, or within the person. And, to return to what brings us together here, in documenting the evidence for this thesis, there is no group whose work I cite more often than yours. For this, my second thank-you.

But don't rest on your laurels too soon. For in a moment, I shall try to exploit the compliment by imposing an obligation. (But, of course, I shall call it an opportunity). Not yet, though, for you still have two more compliments coming. Here's the first one. You, my colleagues, have not only increased our knowledge of the power of proximal processes and relationships, you have applied that knowledge in your own clinical work. As a result, you are the models for the profession.

Finally, in a period when the tragic conditions of life for America's children have escalated to the point where they threaten our national future, there have been no more perspective, persistent, nor more eloquent advocates for children than you.

Who could ask for more? At the risk of your regretting your invitation to say a few words, I can and I shall ask for more—in two domains: first in research, and then in public policy, but of a different kind.

On the first count, to date the best research that has been done on proximal processes—their nature, their power, and the ways in which this power can be activated and harnessed—has been done in the field of infant development; after that, there's not much more to be found. *It is time to break the age barrier*—to investigate the nature, potential, and activation of such processes in middle childhood and beyond. For we are the only species for whom there is no final critical period, beyond which there is no more hope of recovery. For us, the possibility of growth is always there, although it is more difficult to achieve, and may not fulfill the original potential. But nevertheless the child's, and thereby the adult's, life is made not only less painful, but much more rewarding. There is a name for this process in the Holy Writ of many cultures; it is called *redemption*.

I sense that you are not altogether happy to hear that word. Perhaps it is important that it be so. For you are the ones who have the knowledge and the know-how to make redemption work in this life, without waiting for the next. But you must also find the will. Hence my challenge: I am prodding you to extend, adapt, and apply your concepts and your methods to studies of older age groups, where your ideas are still little known, (and where known, left untried), and yet are urgently needed.

In the realm of public policy and practice, there is today an even greater void in this most critical proximal domain. As Ed Zigler can tell you better than I, when Head Start was created we were very fortunate. Then, the big problems were *not* where the money was coming from, which agency would get what part of it, how to coordinate their efforts, or which group of children in need would get which kinds of services under which qualifying, and disqualifying, regulations appearing in the small print. Then, most of our effort, and most of our thought, was focused on the kinds of experiences needed to happen in the daily lives of children and their families that would enable them to do well in school *and* that would continue to happen, on a fairly regular basis for extended periods of time, after the program was over.

In other words, we were primarily concerned with proximal processes. To be sure, at that time we didn't know much about them. We know much more today—to a substantial degree through your efforts.

But you wouldn't think so from the content of today's policy reports, or of any other sources of information outside professional journals and books. Recently I had occasion to examine what current textbooks on child development, and their counterparts in the nation's bookstalls, have to say about the conditions and processes that foster, or undermine, children's development. Once one gets beyond the new demographics of family forms, two-wage-earner households, gender roles, child care, poverty, and minorities—as important as those are—the discussion of what goes on (or should and should not go on) *within* any of these settings is mostly a rather sparse, dull, and curious mix of facts and ideas from the 1960s and the 1970s. It's still "ages and stages," with occasional doses of behavior modification. Nothing important that needs to be done takes longer than just a few minutes—Sesame Street style. The processes mentioned are always one-way, with no turns allowed. There is more talk of parental discipline than of joint activities of parents with their children. Genetics only happen to twins, and they produce their effects all by themselves. Objects and symbols are things used in tests. And the only times that children develop are when they're with somebody else.

But there is one new note from our own time, and that is sounded throughout. The main purpose of it all is to give children "high self-esteem"—not competence, not love, not trust, but self-esteem. (I might add that, to my knowledge, we appear to be the only society, in either the developed or the developing world, that states this as a major goal for children's development.)

This, then, is what is being presented to parents, the general public, and the policy makers as the lessons of modern developmental science.

Yet, there is a selected segment of our population who are learning, at first hand, the *real* lessons of contemporary research and professional experience. Ironically, they are the children and families whose problems are so severe that, even under today's increasingly limited services, they end up in programs of the kind that you have developed and in which you are professionally engaged.

Are we going to leave it that way? Or are we going to share our secret with the public and policy makers? That secret is easy to tell: **In the end, what really matters is what happens to children in their daily lives—on a regular basis and over extended periods of time.** That is what we as researchers and professionals must continue to investigate, better understand, apply in our work, *and* communicate to the general public and its responsible leaders.

You have been, and continue to be, the pioneers in this critical undertaking. For that, I extend an unpromised fifth and final thank-you—and this time, with no strings attached.

In closing, I wish once again to express my deep thanks for the signal honor that you have bestowed upon me.

National Center Notes

by Kathryn E. Barnard

Editors' note: This issue's National Center Notes column is devoted to an adaptation of the Presidential Address delivered by Kathryn Barnard, President of the National Center for Clinical Infant Programs, at NCCIP's National Training Institute, December 7, 1991.

The title of my talk, the first Presidential Address given at an NCCIP National Training Institute, is, simply *Wow!* Although I have been a member of the Board of the National Center for Clinical Infant Programs for a decade or so, it is only since assuming the presidency last spring that I have truly learned what an impressive organization this is. I hope to tell you why NCCIP is impressive, and to engage your participation in our future efforts.

First, however, it is important to understand that NCCIP is not a membership organization. You can't just pay money, sit back, and see what NCCIP can do for you. NCCIP is a **partnership** organization. Anyone can be a partner, and those people who are already involved with NCCIP know the price of partnership: You have to work. We can work together for common goals as core partners—the NCCIP Board; staff; government, foundation, and individual funders—and as "partners-at-large"—people who write for and read *Zero to Three* and NCCIP's other publications; participants in projects like Better Care for the Babies, Promoting Success in Zero to Three Services, Head Start Parent and Child Center Networking and Training, National Early Childhood Technical Assistance System (NEC*TAS) initiatives; and Training of Teams Seminars. **Participation makes you a partner in NCCIP.**

Second, I would like to clarify NCCIP's unique role as a training organization. We are not a university, not a source of training for a single discipline. We are not too involved in passing on ordinary "textbook" knowledge of child development. We are interested in knowledge at the cutting edge, where theory, research, and practice come together to inform training efforts. So in our Fellowship Program, we look for potential leaders who can benefit from, and then help to shape, a vision that combines theory, research, and practice. Our National Training Institute program attempts to include these three elements, as do our intensive courses, training of teams, and technical assistance efforts. A major theme in all of NCCIP's training is the importance of human relationships—between caregivers and children, between parents and helping professionals, and among colleagues.

Third, I would like to emphasize NCCIP's involvement in public policy and social advocacy. We have felt it particularly important to join with other organizations to develop and promote standards of practice, to champion a national infant care leave policy, and to call attention to the crisis in early childhood immunization as part of broader preventive health care concerns. NCCIP's ability to provide a forum for diverse viewpoints is effective—our 1987 infant day care research "summit" meeting, for example, sparked the development of a ten-site longitudinal study under the auspices of the National Institute for Child Health and Human Development.

Virtually every activity of NCCIP results in a publication. Readers of this column who do not have a current NCCIP publications list may request one from the National Center.

What are NCCIP's plans for the future? As we begin our fifteenth year as an organization in 1992, we have before us a recently developed agenda for action. This agenda affirms our understanding of the importance of the first three years of life to the healthy development of children, and our awareness that the circumstances of many of our nation's children and families during this critical period is far from optimal. We believe that many of the factors that mark the difference between an optimal and a non-optimal environment can be changed—this gives us the drive and passion to carry on, to make this a better world for very young children and their families.

NCCIP's efforts over the next five years will focus on both the setting and the policy context in which services to strengthen the development of infants, toddlers, and their families are delivered.

- **NCCIP will exercise leadership in developing and communicating a national vision of the importance of the first three years of life.**

- **NCCIP will endeavor to convince policymakers and policy shapers that *prevention* (the reduction of risk and the promotion of protective factors) in the first three years of life is essential to healthy growth and development.**

To further these ends, we propose to continue current activities and begin new initiatives for: facilitating the exchange and dissemination of clinical and research knowledge about infancy, toddlerhood and families; identifying ongoing or emerging issues that affect early development; collecting and analyzing data relating to the efficacy of prevention and early intervention; and enlisting the assistance of a broad range of opinion makers.

During the next five years, NCCIP will also address issues of "best practice" in services to infants, toddlers, and their families.

- **NCCIP will promote the exploration and dissemination of the highest possible standards of practice to support infants, toddlers, and their families.**

- **NCCIP will work to improve the training of infant/family practitioners.**

We plan to: develop a document or documents that identify and explore the meaning of "standards of practice" in our field; describe "best practice" in specific areas, including screening and assessment, diagnostic classification of emerging developmental problems,

family-centered training, supervision and mentorship, and program evaluation; identifying and reaching out to underserved groups and populations; identifying and fostering future leaders in the field; developing models of multidisciplinary training and practice; encouraging a major commitment to improved and expanded training by state policymakers and private funders; and serving as a central resource for information about the training of people who work with infants, toddlers, and their families.

I hope that I have conveyed to you a sense of the power within the National Center for Clinical Infant Programs. We are up to the challenge of helping to make this country a better place for all very young children and their families—if we can engage all of you in partnership toward this goal. We encourage your participation.

To the Editors:

What a wonderful article, "Learning Through Supervision and Mentorship to Support the Development of Infants, Toddlers and Their Families"! I have been working with infants and toddlers and their families for the past twelve years—both in providing direct service to the families as well as supervising those who go out to work with families.

When I first became involved with the Early Intervention Program at the local ARC, I had a degree and experience with learning disabled children from five to eighteen years old. When I accepted the position as an Early Intervention Specialist (we were called Home Trainers then!), I had no formal training or experience with this age group or with families. The training I received at the beginning of this job consisted of accompanying the other trainer on one day of home visits and I was then expected to go out and do visits on my own. Needless to say, I was not exactly confident in my ability to serve these families, but after years of working and learning through trial and error, I feel that my knowledge and expertise have grown immensely.

When I was working on my Master's degree, I focused my attention and research on the field of Early Intervention and was able to broaden my knowledge base through these efforts. Other than the coursework and research during school, all of my training was the result of endless questioning, continuous reading and researching, and trial and error. How I would have loved to have had a supervisor who would have helped me along the way!

My first director never accompanied me on any home visits (other than to do an evaluation of my performance) and, therefore, had no idea of the various frustrations and idiosyncracies involved in making home visits. Therefore, she was unable to relate to and understand some of the problems incurred during these visits. Only those individuals who have held positions that involve making home visits can fully understand all the things that can happen while you are there ... the things that go right, the things that go wrong, crises that may arise, etc., etc., etc. This director was not sympathetic to situations that would arise where the actual purpose for the visit was altered ... where a crisis may have occurred while I was there, mother needed to talk or vent her frustrations to continue with her life at that moment, or the child was not in an amiable mood, etc. What takes place on a home visit cannot always be controlled as in a classroom situation. I feel so strongly that anyone who directs individuals who make home visits to families should be someone who has made home visits herself (or himself). Only then can the supervisor fully understand what can actually happen on these home visits. How frustrating it was for me to try to explain why I had not completed a lesson plan or my contact notes did not show any developmental activities!

The first director moved on and the new director who took her place had actually made home visits. I then felt that I no longer had to constantly justify and defend my actions on visits and the new director and I developed a relationship of mutual respect and trust. I was then able to relax and felt comfortable relaying information to her about my home visits. She would then give me support, advice, and alternative suggestions to try. What a difference it made!

I have now been a supervisor of home visitors. One program was with degreed, certified people and the other with paraprofessionals. Both groups make home visits and work with young children and their families. Both groups have their strength and weaknesses, however different, yet both groups have many similar concerns. Because of my experience with working with families, I hope that I have been able to relate to the two groups and understand the kinds of things that they are experiencing.

Your article will remain a permanent fixture in my office that I will refer to on a regular basis to refresh my memory on how I can better assist my staff in delivering services to children and their families. Thank you for writing this article. I hope that it will make a difference in how programs and trainings are conducted.

This field is relatively new, even though there are some who have been doing this for years. I will be glad when there is a specific program and course outline directed to the field of Early Intervention at the local university. I would love to be a part of the teaching of that track!

Sincerely,
Suzanne Healey
Pensacola, Florida

Publications:

Interventions with Infants and Parents: The Theory and Practice of Previewing (1992) - Paul V. Trad (Wiley-Interscience, John Wiley & Sons, Inc., 605 Third Avenue, New York, NY 10158-0012) $55.00.

As Director of the Child and Adolescent Outpatient Department at Cornell Medical Center—Westchester Division, Paul Trad has been involved in the treatment of pregnant women and new mothers, observing the caregiver's unique and distinctive relationship with the infant unfolding directly in front of the therapist. This volume offers an approach to identifying and assessing maladaptive patterns in caregiver-infant relationships and introduces intervention techniques to improve dyadic relationships.

Central to Trad's intervention approach is the phenomenon of *previewing*, defined as the process whereby parents anticipate and nurture imminent developmental changes in their infants. Trad suggests that the incidence of previewing behavior is one of the most effective means for diagnosing the adaptiveness of a caregiver-infant dyad. To be able to preview imminent developmental changes to the infant, the caregiver must first possess some fundamental knowledge about the scope of upcoming maturational achievements and must be able to envision, or "represent" the infant attaining these achievements. Trad discusses a variety of intervention techniques that therapists can use to help parents gain knowledge of overall development, be more sensitive to the individual infant's unique capacities, and explore past conflicts that may be interfering with the relationship with the infant.

An Activity-Based Approach to Early Intervention (1992) - Diane Bricker and Juliann J. Woods Cripe (Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624) $24.00.

Activity-based intervention, according to Bricker and Cripe, is a combination of selected strategies found in early childhood and "behavior analytic" approaches to intervention with young children with, or at risk of, disabilities. The approach involves following children's leads and interests, targeting objectives, and monitoring progress. It "embeds intervention on children's individual goals and objectives in routine, planned, or child initiated activities." In this approach, multiple targets from a variety of developmental domains can be addressed in single activities. Moreover, activities that children choose themselves provide intrinsic motivation for engaging in them.

The book describes aspects of activity-based intervention and the effectiveness of the approach, outlines the knowledge and skills needed by interventionists using the approach, and suggests planned activities appropriate for children at different developmental levels.

Strategies for Teaching At-Risk and Handicapped Infants and Toddlers: A Transdisciplinary Approach (1991) - Sharon A. Raver (Macmillan Publishing Company (Merrill), 866 Third Avenue, New York, NY 10022) $40.00.

This book is organized around the transdisciplinary approach to early intervention services, an approach that involves not only the mutual sharing of assessment results but also professional involvement and participation that crosses traditional discipline boundaries. In this approach, professionals work together, with the direct guidance of a family, to develop a unified and integrated plan for the child and family.

Chapters in this volume present intervention strategies for developmental domains, intervention strategies for medical settings, and intervention strategies for specific populations, as well as discussions of the transdisciplinary approach, working with families, and the Individualized Family Service Plan process. Contributors in addition to Dr. Raver include Toby Long, Lou Rossetti, Eva K. Thorp, Cordelia Robinson, Barbara Jackson, Doris Bergen, Mary E. McLean, Mary Beth Bruder, Samera Baird, Carl Dunst, Marilyn Sass-Lehrer, Kay Alicyn Ferrell, and Jennifer Kilgo.

Supporting Families with a Child with a Disability: An International Outlook (1991) - Alan Gartner, Dorothy Kerzner, Lipsky, and Ann P. Turnbull (Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624) $25.00.

This book is designed to address three intertwined issues—disability, culture, and family, and the ways in which they play themselves out in the lives of families with a child with a disability. It is the second product of a 1988 cross-cultural conference that included participants from Australia, Canada, Israel, Japan, Kenya, Sweden, the United Kingdom, the United States, and Uruguay. The book reflects an awareness that physical and social environments determine the extent to which an individual's impairment becomes a handicap.

The authors explore historic and anthropological antecedents of different cultures' responses to families with a child with a disability. They discuss aspects of family support systems including financial assistance, education, employment, housing, recreation, and respite care. A final chapter offers specific observations on each of the nine study countries as well as contrasts between "traditional" and "state-of-the-art" family support services. The authors conclude:

> Children with disabilities are neither rewards to nor punishments for their families, although at times, as with all children, they may seem like either or both. And, as with all children, they present both burden and opportunity to the family. They are entitled, as are all children, to be nurtured and loved, to hope and aspire, to have opportunities to contribute to society, to live in the community with family and friends.

Saving Children At Risk: Poverty and Disabilities (1992) - Travis Thompson and Susan C. Hupp, editors (Sage Publications, Inc., 2455 Teller Road, Newbury Park, CA 91320) $21.95.

This book includes updated versions of presentations made originally at a conference held at the University of Minnesota in late, 1989. In an effort to promote a longer range perspective on preventing disabling conditions and intervening early in the lives of children with disabilities, contributors examine four sets of issues:

- the range of preventable disabling conditions, reasonable expectations, and strategies for their prevention;
- perinatal influences on development;
- environmental interventions to ameliorate effects of perinatal and postnatal risks and/or disabilities; and
- a national plan of action for prevention of disabilities and early intervention in high-risk situation.

Contributing authors include Duane Alexander, Alfred Baumeister, Judith Brown, Dennis Cabral, Judith Carta, James Gallagher, Norman Garmezy, Laraine Masters Glidden, Susan Hupp, Luann Klindworth, Frank Kupstas, John Rynders, and Travis Thompson.

Infants in Crisis: How Parents Cope with Newborn Intensive Care and Its Aftermath (1991) - Glen Affleck, Howard Tennen, and Jonelle Rowe (Springer-Verlag New York, Inc. 175 Fifth Avenue, New York, NY 10010) $49.00.

This volume presents findings from a study that, beginning in 1984, followed 114 families with babies who were hospitalized on the NICU at the University of Connecticut Health Center in Farmington, Connecticut. The vast majority of the babies were born prematurely, and the average child spent almost two months on the intensive care unit. In the year and a half after discharge from the NICU, infants received a spectrum of early intervention services; half of the families were randomly assigned to an experimental transitional support program during the first three months after discharge.

In-depth interviews with parents revealed that phases of the "unfolding crisis" of newborn intensive care should be understood as including pregnancy (difficult or uneventful), hospitalization, the transition home (with new coping burdens), and longer term health and developmental outcome (often uncertain). Researchers found that parents' successful searches for meaning and mastery helped cognitive adaptation to the unfolding crisis. The study also explored mothers' strategies of coping with their child's hospitalization (e.g., taking instrumental action, mobilizing social support, seeking meaning, escaping, minimizing), their determinants, and their long-term consequences.

In discussing the implications of their findings for helping professionals, the authors note:

> The findings of this study defy any ... categorization of stages of adjustment to the crisis of newborn intensive care. If anything, they document exceptional variability in parents' coping and adaptation ... When professionals hold stereotyped expectations of parental adjustment, their efforts to provide support are jeopardized and their relationship with parents will suffer.

Infants and Young Children with Special Needs: A Developmental and Ecological Approach, Second Edition (1990) - S. Kenneth Thurman and Anne H. Widerstrom (Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624) $40.00.

This volume is designed to provide effective preparation for personnel training to work in the field of early intervention through its emphasis on both typical and atypical child development, combined with an ecological view of intervention. The first section of the book is devoted to a developmental perspective. Chapters examine typical and atypical development in various domains, as well as clarifying the concept of integration or "least restrictive environment" for children from birth to age 5. Chapters in the second section of the book, designed to offer an ecological perspective, discuss ecological assessment of infants, children, and families, and address aspects of program planning and intervention.

HIV Infection and Developmental Disabilities: A Resource for Service Providers (1992) - Allen C. Crocker, Herbert J. Cohen, and Theodore A. Kastner, editors (Paul H. Brookes Publishing Company, P.O. Box 10624, Baltimore, MD 21285-0624) $47.00.

This volume addresses concerns related to children and adults, at all levels of expression of infection with human immunodeficiency virus. A large section of the book focuses primarily on children with congenital HIV infection, considering such issues as:

- What services should or can be provided within the generic service system?
- How much special (but not segregated) care needs to be provided?
- What are the unique needs of families and caregivers of children with HIV infection and how can these needs be met?
- How should services be coordinated and interagency collaboration be achieved?
- How and to what extent should confidentiality be maintained?
- What are the hopes for the future in terms of medical, educational, and social or psychological interventions?

Chapter authors for this section include Gary Diamond, Herbert Cohen, Jenny Grosz, Brigitta Mueller, Philip Pizzo, Sheri Rosen, Michele Granger, Meredith Hinds Harris, L. Jean Emery, Geneva Woodruff,and John Seidel, among others.

A section on policy considerations, including contributions by Allen Crocker and others, addresses issues of legal rights, financing, training, public opinion, and prevention.

At-Risk and Handicapped Newborns and Infants: Development, Assessment, and Intervention (1991) - Anne H. Widerstrom, Barbara A. Mowder, and Susan R. Sandall (Prentice-Hall, Inc., A Division of Simon & Schuster, Englewood Cliffs, NJ 07632) $46.00.

Provision of effective services for disabled and at-risk infants and newborns requires, according to the authors of this volume, that professionals be knowledgeable and skilled in their own discipline, knowledgeable in related disciplines and open to the expertise of others, flexible in thought and action, and sensitive to the strengths, needs, hopes, and desires of families. In addition to serving as a text for graduate-level study and beyond, this book is designed to help educators and psychologists in health care, and health care professionals working in education and psychology to become conversant with the literature, research, and intervention premises associated with other related disciplines. The volume contains chapters on typical infant development, determinants of risk in infancy, and developmental disorders in infancy. A special chapter is devoted to preterm and low birthweight infants. A discussion of family dynamics includes theoretical perspectives, research findings, and a rationale for family-focused early intervention approaches. Early intervention with at-risk and handicapped newborns and infants is reviewed historically and discussed from perspectives of screening and assessment, service planning, intervention techniques, program models, and ethical analysis.

Conference Call:

March, 1992

March 11-14: *The National Association of Pediatric Nurse Associates and Practitioners (NAPNAP)* will sponsor its 13th Annual Nursing Conference on Pediatric Primary Care in San Antonio, Texas. T. Berry Brazelton will deliver the keynote address. Write to NAPNAP Conference Office, North Woodbury Road/Box 56, Pitman, NJ 08071.

March 12-13: The *Family, Infant and Preschool Program, Western Carolina Center* will hold its 9th Annual Smoky Mountain Winter Institute in Asheville, North Carolina. Faculty will include Arnold J. Sameroff, Donna Bryant, Carl Dunst, Byron Egeland, Wesley Brown, Jean Gowen, Karen O'Donnell, and Douglas Powell, among others. Write to Family, Infant and Preschool Program, 300 Enola Road, Morganton, NC 28655.

March 23-28: The *Southern Association on Children Under Six* will hold its 43rd Annual Conference, entitled "One Voice for Children," in Tulsa, Oklahoma. George Henderson, Lillian Katz, Milly Cowles, Betty F. Bumpers, and Helen Blank will be featured speakers. Contact SACUS, P.O. Box 5403, Little Rock, AR 72215-5403, tel: (501) 663-0353.

April, 1992

April 9-11, May 13-15: The Tenth Annual Series of *National Conferences of Neonatal Nursing* will be held in Boston, Massachusetts and Orlando, Florida, focusing on care of the sick neonate. Contact Contemporary Forums, 530 La Gonda Way, Suite E, Danville, CA 04526, tel: (510) 820-2800.

April 11: The *Boston University School of Medicine* will present a seminar on "Dilemmas in Infant Growth and Nutrition" in Cambridge, Massachusetts. Faculty will include Howard Bauchner, Elizabeth Brown, Deborah Glotzer, Alan Meyers, Vivian Morris, Benjamin Siegel, Christine Tinstman, Brian Forsyth, and Ruth Lawrence. Write or call Department of Continuing Medical Education, Boston University School of Medicine, 80 East Concord Street, A305, Boston, MA 02118, tel: (617) 638-4605.

April 12-14: The *National Center for Family Literacy*, together with 23 co-sponsoring state and national organizations, will hold the First National Conference on Family Literacy in Chapel Hill, North Carolina. The conference theme is "Reaching America's Education Goals through Family Literacy." Contact Sharon Darling, National Center for Family Literacy, 401 South 4th Avenue, Suite 610, Louisville, KY 40202-3449, tel: (502) 584-1133, FAX: (502) 584-0172.

April 22-24: *Harvard Medical School's Department of Continuing Education* will present the Eighth Annual Conference on Abuse and Victimization in Life-Span Perspective, entitled "Mothers: Victimization, Stigma, and Survival," in Boston, Massachusetts. Conference directors are Carolyn Moore Newberger and Eli Newberger; faculty will include, among others, Susan Barkan, Ellen Bassuk, David Gil, Carol Gilligan, and Kathleen White. Contact Harvard MED-CME, P.O. Box 825, Boston, MA 02117, tel: (617) 432-1525.

April 29-May 1: The *California Center for Childhood Injury Prevention* of the *Graduate School of Public Health, San Diego State University* will hold the Sixth Annual Childhood Injury Control Conference in San Francisco. It will focus on injury control priorities, new research, and injury prevention program models. Contact Michelle Ur, Conference Coordinator, California Center for Childhood Injury Prevention, San Diego State University, 6505 Alvarado Road, Suite 205, San Diego, CA 92120, tel: (619) 594-3691.

April 30-May 2: The *American Bar Association Center on Children and the Law* will hold the Sixth National Conference on Children and the Law in Arlington, Virginia, entitled "Not Just a Commitment ... A Career." Contact: ABA Center on Children and the Law, 1800 M Street, N.W., Washington, DC 20036, tel: (202) 331-2256.

April 30-May 3: *Save the Children's Child Care Support Center* will sponsor the 15th Annual Family Day Care Technical Assistance Conference in Atlanta, Georgia. Contact

Save the Children/Child Care Support Center, 1340 Spring Street N.W., Suite 200, Atlanta, GA 30309, tel: (404) 885-1578.

May, 1992

May 3-6: The *Center for Developmental Disabilities* will sponsor the seventh annual National Symposium on Information Technology in Myrtle Beach, South Carolina. Topics to be addressed include providing information and referral services, case management and client tracking systems, and innovative applications of information technology. Contact National Symposium on Information Technology, Center for Developmental Disabilities, University of South Carolina, Benson Building, 1st Floor, Columbia, SC 29208, tel: (803) 777-4435, FAX: (803) 777-6058.

May 6-9: The *Family Resource Coalition* will hold its Fourth National Conference, entitled "Family Support: Framework for the Future," in Chicago, Illinois. Bernice Weissbourd and Marion Wright Edelman will be keynote speakers. Contact Stephanie Lubin, Family Resource Coalition, 200 S. Michigan, Suite 1520, Chicago, IL 60604, tel: (312) 341-0900, FAX: (312) 341-0361.

May 7-8: The *Office of the Superintendent of Public Instruction* and the *Early Childhood Development Association of Washington* will hold an Infant and Early Childhood Conference entitled "Children, Families and Professionals: Promoting Partnerships in the Community" in Seattle, Washington. Direct inquiries to P.O. Box 15705, Seattle, WA 98114, tel: (206) 526-0870.

May 7-8: The *Pennsylvania Early Intervention Providers Association* and the *Pennsylvania Council for Exceptional Children's Division of Early Childhood* will hold their annual conference in Harrisburg, Pennsylvania, with the theme, "The Early Intervention Collage—Every Piece Counts!" For information, contact Kathleen Pacca, Special Needs Coordinator, Child Development Council of Northeastern Pennsylvania, PO Box 1142, Wilkes-Barre, PA 18703-1142, tel: (717) 829-2446.

May 8-9: *Education Resources, Inc.* will present a conference in Newark, New Jersey on "Cocaine Exposed Babies: Crisis, Challenge, and Opportunities," with Barry Zuckerman, among other faculty. Contact Education Resources, Inc, 1o Park Steet, Suite 2, Medfield, MA 02052, tel: (508) 359-o533 or (800) 487-o530 (outside MA).

May 13-16: The *Norwegian Centre for Child Research* will sponsor an international interdisciplinary conference on "Children at Risk" in Bergen, Norway. Plenary speakers will include James P. Grant, Bernadine Dohrn, Michael Rutter, Noboru Kobayashi, and Trond Viggo Torgersen. Contact The Norwegian Centre for Child Research, The University of Trondheim, N-7055 Dragvoll, Norway, tel: 47-7-59 62 44, FAX: 47-7-59 62 39.

May 16: The *Jefferson Medical College* and *The Philadelphia Psychoanalytic Society and Institute* will hold the 23rd Annual Margaret S. Mahler Symposium in Philadelphia, with the title "Prevention in Mental Health: Today, Tomorrow, Ever?" Featured speakers will be Byron Egeland, Eleanor Galenson, Henri Parens, and William Singletary. For information, write to Gloria Schwartz, 1201 Chestnut Street, 14th Floor, Philadelphia, PA 19107.

May 21-22: *Beginnings Early Intervention Services,* the Pennsylvania Chapter of the *American Academy of Pediatrics,* and *Project Caring* will sponsor a conference in Pittsburgh, Pennsylvania on "Creating Family-Professional Partnerships: Educating Physicians and Other Health Professionals to Care for Children with Chronic and Disabling Conditions." Keynote speakers are Florene Poyadue and Alfred Healy. Contact Beginnings at 406 Main Street, Suite 201, Johnstown, PA 159-1, tel: (814) 539-1919.

June, 1992

June 3-6: The *National Institute for Early Childhood Professional Development* of NAEYC will hold a working conference in Los Angeles, CA entitled "The Early Childhood Profession Coming Together." Its purpose will be to address issues of content, policy, and delivery systems related to the implementation of an artiulated professional development system for the field of early childhood education. A post-conference technical assistance workshop will be offered by the Wheelock Center for Career Development in Early Care and Education. Contact the National Institute for Early Childhood Professional Development, NAEYC, 1834 Connecticut Avenue, N.W., Washington, DC 20009, tel: (202) 232-8777 or (800) 424-2460, FAX: (202) 328-1846.

June 15-19: The *College for Human Development and Division of Summer Sessions of Syracuse University* will sponsor Alice Honig's 16th Annual Quality Infant/Toddler Caregiving National Workshop in Syracuse, New York. Faculty will include Alice Honig, William Fowler, Andrea Monan, Susan Snyder, Mary Anne Theiss, Thomas Fiscoe, and John Friedman. Write or call Alyce Thompson, College for Human Development, Dept. of Family and Child Studies, 201 Slocum Hall, Syracuse, NY 13244-1250, tel: (315) 443-2757.

June 24-26: The fifth annual *Bank Street College of Education Infancy Institute,* entitled "Infants, Toddlers, Parents: Supporting Their Growth," will be held in New York City. Bettye Caldwell will be the keynote speaker. All-day seminars on observing infants and toddlers and working with families of varied cultures will be offered. Contact Dr. Nancy Balaban or Dr. Virginia Casper, Bank Street College of Education, 610 West 112th Street, New York, NY 10025, tel: (212) 222-6700, x 410 or 335.

Zero to Three

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